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A Study into the Lived Experience of Autistic Adults Relationships

Amber-Sophie Dugdale

May 2020

A thesis submitted in partial fulfilment of the requirement for the award of Doctor of Clinical
Psychology

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Word Count

Section One: Systematic Literature Review

| | |
|---|--------|
| Excluding references and tables | 7998 |
| Including references and tables | 12,517 |
| Including references, tables and appendices | 13,974 |

Section Two: Empirical Study

| | |
|---|--------|
| Excluding references and tables | 8000 |
| Including references and tables | 11,061 |
| Including references, tables and appendices | 18,640 |

Total Word Count

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|---|--------|
| Excluding references and tables | 15,998 |
| Including references and tables | 23,578 |
| Including references, tables and appendices | 32,614 |

Overall Abstract

Autism Spectrum Condition is characterised by social interaction and communication difficulties which impact psychosocial wellbeing. Research on autistic individuals' social experiences has typically focused on children or interventions to support social functioning. Qualitative research allows for a deeper exploration of lived experiences. A literature review was carried out to explore the current qualitative literature into autistic adults' experiences of relationships. Four databases were searched resulting in twenty-one included studies which were analysed using Thematic Synthesis. Results indicated that autistic individuals experience relational difficulties, such as issues with social rules or indirect communication. However, there was a strong theme that suggested moving away from a 'deficit' narrative within autism to a 'difference' narrative could be helpful, as difficulties with socialising were not from being autistic, but rather from issues associated with holding a minority status. For example, having an awareness of difference (leading to anxiety), the 'double empathy problem', experiences of victimisation, and internalised shame. Despite difficulties, autistic adults have a desire for and successfully form and maintain relationships, which has a positive impact on their wellbeing. Strategies such as self-acceptance, planning and structure were beneficial in supporting relationships.

A research study into the experiences of autistic parents was also conducted. Parenthood is associated with positive and negative experiences (for example, connection and increased stress). Autistic parents may experience unique strengths and challenges. A qualitative design, of Interpretative Phenomenological Analysis, was utilised. Nine autistic mothers to children (aged 5-15 years) participated in semi-structured interviews. Results

indicated that autistic parents experience similar parenting ups and downs to non-autistic parents (such as, enjoyment, connection and increased stress). Autistic parents also experience unique strengths and challenges. Misunderstandings and judgements from professionals were most challenging. Participants' children typically also had a diagnosis of Autism Spectrum Condition and this shared diagnosis strengthened the parent-child bond, but also led to increased judgements.

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Section One: Literature Review

A Thematic Synthesis of Autistic Adults Lived Experiences of Non-Familial Relationships

Abstract

Objectives

Autism Spectrum Condition is characterised by social interaction and communication difficulties which impact psychosocial wellbeing. Research on autistic individuals' social experiences has typically focused on youth, interventions, and their outcomes. Qualitative research allows for a deeper exploration of lived experiences. This review aimed to explore the current qualitative literature into autistic adults' experiences of relationships.

Design and Methods

Four databases were systematically searched for qualitative studies on autistic adults' relationship experiences. Twenty-one studies were included, assessed for quality (utilising Joanna-Briggs Institute Critical Appraisal Checklist) and analysed using Thematic Synthesis.

Results

Four superordinate themes were found; '*Relational Difficulties*'; '*Different Needs and Expression*'; '*Same as Everybody Else*'; and '*What Helps?*'.

Conclusions

Moving from a 'deficit' narrative to a 'difference' narrative within autism could be helpful. The review highlighted difficulties with socialising were not from being autistic, but rather from issues associated with holding a minority status, such as awareness of difference (leading to anxiety), the 'double empathy problem', experiences of victimisation, and internalised shame. Despite difficulties, autistic adults have a desire for, and successfully form and maintain, relationships, which has a positive impact on their wellbeing. Strategies such as self-acceptance, planning and structure were beneficial in supporting relationships.

Practitioner Points

- Future research may consider neuro-mixed relationships versus autistic-autistic dyads in order to further understand the impact of the 'Double Empathy Problem'.
- Autistic adults would benefit from tailored services and education that adopts a narrative of 'difference' rather than 'disability'.

Keywords

Autism; ASC; Qualitative; Thematic Synthesis; Relationships; Friendships; Adult; Systematic Review.

Introduction

Autism Spectrum Condition¹ (ASC) is a lifelong neurodevelopmental condition that impacts social communication, social interaction, behaviour and interests (American Psychiatric Association, 2013). In particular, autistic² individuals have difficulties with social reciprocity, non-verbal communication (American Psychiatric Association, 2013), executive functioning (for example, flexibility, planning; Verté et al., 2006), and sensory processing (Hilton et al., 2010). These difficulties, in turn, impact autistic individual's psychosocial wellbeing (Chown, 2015). Specifically, autistic individuals have been found to experience lower social acceptance (Strang et al., 2012), increased difficulties in interpersonal relationships (Levy & Perry, 2011), as well as increased isolation and loneliness (White & Roberson-Nay, 2009).

The impact of these social difficulties is reflected in autistic individuals poorer quality of life (Van Heijst & Geurts, 2015; Howlin et al., 2013), reduced social resources (Autism Speaks, 2017), increased mental health difficulties (Croen et al., 2015; Gillott & Standen, 2007; Hofvander et al., 2009; Maddox & White, 2015), specifically that of depression and anxiety (Buck et al., 2014; Lever & Geurts, 2016), and increased suicide attempts (Cassidy & Rodgers, 2017), compared to the general population.

Increased anxiety in autistic individuals exacerbates executive functioning and social difficulties (White et al., 2010), creating a negative

¹ Autistic individuals prefer the term ASC compared to Autism Spectrum Disorder, which is the diagnostic term (Kenny et al., 2015).

² The majority of autistic individuals, families and friends preferred identity first language (i.e. autistic) compared with first person language (i.e. person with autism; Kenny et al., 2015).

feedback cycle. Additionally, autistic individuals are at higher risk of bullying and victimisation (Schroeder et al., 2014); likely associated with social difficulties and further compounding mental health difficulties (Kloosterman et al., 2013). Linked to this, evidence suggests that the media and general public hold negative stereotypes of autistic individuals, such as depicting them as emotionless or having “difficult personalities” (Harnum et al., 2007; Wood & Freeth, 2016; Treweek et al., 2018). These stereotyped beliefs can impact individuals negatively (Mogensen & Mason, 2015) and may make it harder for them to form friendships, despite their desire for them (Daniel & Billingsley, 2010).

Given these social difficulties and their impact, it is important that autistic individuals’ social experiences of relationships are more thoroughly explored, from their own perspective. This could aid in challenging the over-simplified and inaccurate stereotypes, increasing positive views of autism, as well as supporting tailored interventions. This may be of particular relevance to professionals in healthcare services, such as mental health services, as Vannucchi et al. (2014) found that mental health comorbidity was the primary reason for autistic adults to seek support from professionals. However, research to date on social interaction in autistic individuals has largely focused on outcomes (Zimmerman et al., 2018) or interventions to improve skills, as well as their efficacy (for example, social skills training (Moody & Laugeson, 2020), computer and robot assisted therapies (DiPietro et al., 2019), animal-assisted interventions (Tan & Simmonds, 2019; Hill et al., 2019), social stories (Karal & Wolfe, 2018)). Additionally, the majority of this intervention research is focused on children or adolescents and there is a limited evidence base for psychosocial interventions in adults (Pallathra et al., 2019). Howlin et al. (2015) highlights

how literature on autistic individuals in general follows this pattern; adult literature is limited compared to research on children, and largely focuses on outcomes (for example, quality of life, mental health diagnosis). Although valuable, outcome and intervention focused research alone may potentially miss experiences and factors that autistic individuals themselves feel are relevant.

Current research indicates that social difficulties and their impact are prevalent throughout adolescence and adulthood in autistic individuals (Poon & Sidhu, 2017; Howlin & Magiati, 2017). Considering the different social pressures and experiences throughout stages of life, it is important that the experience of socialising is better understood among all autistic age groups. Howlin and Magiati (2017) and Murphy et al. (2016) in particular advocate that more thorough research into the experiences of difficulties across autistic adulthood is needed. Similarly, autistic adults have reported they feel factors impacting their day-to-day lives are under-researched (Pellicano et al., 2014).

In order to better understand lived experiences of autistic adults' social relationships, qualitative research provides an essential method to explore the nuances of this. Such methods may particularly facilitate giving a voice to people who are "*often studied but seldom heard*" (Ferguson et al., 1992, p.14). Qualitative reviews synthesising related topic areas within autism have previously been successfully completed (for example, experiences of siblings of autistic individuals (Leedham et al., 2020), experiences across stages of developments (DePape & Lindsay, 2016)). A qualitative review of autistic youth (aged 10-19) experiences of peer relationships has also been completed, showing many overcame social difficulties due to a desire for friendship (Cresswell et al., 2019). Some reviews have also been carried out into autistic

individuals' experience of sexuality, however these have been in relation to gender dysphoria (Øien et al., 2018), sex education (Sala et al., 2019), or focus on quantitative data only (Parchomiuk, 2019). There is, however, no review of qualitative research on the social and relationship experiences of autistic adults, to date.

This study, therefore, aims to systematically identify, critically appraise, and review current qualitative research investigating lived experiences of autistic adults' non-familial relationships. Specifically, it aims to generate a thematic synthesis, identify gaps and limitations in the extant literature, and consider clinical implications.

Method

The protocol for this systematic review was registered on the international prospective register PROSPERO (Reference: CRD42020168464). This review took a narrative synthesis approach, largely influenced by the approach described by Thomas and Harden (2008).

Search Strategy

Scopus, PsycINFO, Medline, and Google Scholar databases were searched between December 2019 and March 2020. Search terms on Scopus, PsychINFO and Medline were ("Autis*" OR "Autis* Spectrum" OR "Asperger" OR "Pervasive Developmental Disorder") AND ("Lived Experience*" OR "Qualitative" OR "Content" OR "thematic" OR "discourse" OR "narrative" OR "template" OR "grounded theory" OR "interpretative phenomenolog*" OR "conversation*") AND ("social" OR "relation*" OR "friends*" OR "sex*" OR "romantic" OR "partner" OR "marital" OR "marriage" OR "Same sex" OR "LGBT*") AND ("Adult"). The symbol * was used for truncation. Title, abstract, and keyword was searched for. The search was adapted for Google Scholar

due to its differential platform but included as many similar search terms to the above as possible; title was only searched in Google Scholar.

Selection Criteria

The following inclusion and exclusion criteria were utilised to ensure only relevant articles were included:

Inclusion Criteria

1. The majority of participants are autistic adults (aged 16 or over³).
2. Utilisation of a qualitative methodology and analysis.
3. The aim of the study was to explore or comment on a relational experience (for example, friendships, romantic partners, sexual experiences, coping with social situations).
4. Articles published in a peer-reviewed journal.

Exclusion Criteria

1. Not published in English.
2. Majority of participants have a diagnosis of Learning Disability.
3. Focus on family relationships only.
4. Focus on professional or employment-based relationships.

Screening

Initial screening was carried out by title and abstract, with articles removed based on the above exclusion criteria. Duplicates were removed and

³ Although the legal age of adulthood is considered 18 years of age in England (HMRC, 2011) some countries, such as, Scotland (HMRC, 2011), Cambodia (Youth Policy, 2014a) Cuba (Youth Policy, 2014b), recognise 16-year-olds as legal adults. Additionally, a majority of countries allow 16-year-olds to have legal rights typically associated with adulthood such as being able to vote (ACE Electoral Knowledge Network, 2018), have sex and become a parent (Age of Consent, 2020), or be conscripted into the military (CIA, 2019). To be inclusive of various cultures the study therefore had 16 years as the cut off age for inclusion.

then full-text screening was completed. Forward and backward tracking was completed on key papers. Forward tracking citations were completed using Scopus.

Data Extraction

The following data was extracted from included articles: author; year of publication; country of study; data collection; qualitative design for analysis; available sample demographics (number, age, gender, diagnoses); summary of key findings or themes.

Assessment of Quality

Thomas and Harden (2008) advocate quality assessments in qualitative reviews; they utilise their own criteria specific to their review topic which, therefore, was not appropriate for this study. Alternatively, a well-established qualitative assessment tool was utilised on all included articles: Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research (JBI-CACQR; Appendix A; Joanna Briggs Institute, 2017).

Thomas and Harden (2008) do not exclude articles based on quality as they argue there is no evidence to support doing so in qualitative research. Alternatively, they conduct a “sensitivity analysis”; where the study’s contributions to the themes are assessed in relation to the study’s quality (Carroll & Booth, 2015). The current review, therefore, utilised this out following the quality review with JBI-CACQR.

JBI-CACQR contains ten questions which can be answered ‘yes’ (item sufficiently considered), ‘no’ (item not sufficiently considered), ‘unclear’ (not clear, or insufficient information), or ‘not applicable’; there are no standardised scores or categories (i.e. ‘good’, ‘poor’ quality). In this review, scores and categories were pre-decided by the lead researcher after reviewing JBI-CACQR

(as well as reviewed and agreed with two researchers⁴) to aid the sensitivity analysis. 'Yes' received a score of 1, 'no' and 'not applicable' scores of zero, and 'unclear' a score of 0.5 (giving a total out of 10). Appendix B shows relevant scoring categories.

Around 20% of included articles (n=5) were appraised by a second reviewer⁵. There were two discrepancies; one on item eight⁶ of JBI-CACQR and one on item nine (from two separate papers). These were resolved via a discussion and resulted in another check of all other papers for consistency.

Data Synthesis

Data was reviewed and narratively synthesised using Thematic Synthesis (Thomas & Harden, 2008). Verbatim text from the "results" sections was exported into a Microsoft Excel table for line-by-line coding. Some articles included data from non-autistic populations, quantitative data, or had results from questions not related to the aims (for example, employment experience); only data from autistic populations that reflected on social experiences were exported. Codes focused on the content and meaning of each line. As this was completed for each study, codes were translated and added to a 'bank of themes'. Codes across the studies were compared and grouped into a hierarchal structure in order to give descriptive themes. These descriptive

⁴ Professor Nigel Beail (Consultant Clinical Psychologist): Primary Supervisor & Professor Andrew Thompson (Consultant Clinical Psychologist): Secondary Supervisor.

⁵ Professor Nigel Beail (Consultant Clinical Psychologist): Primary Supervisor.

⁶ Item eight refers to ethical approval of the studies. It was agreed items scored 'yes' for ethical approval if this was appropriate for the country the study was carried out in, not for country the review is carried out in (UK).

themes were then further interpreted to give a list of superordinate and subthemes; this was completed by, and agreed with, a second researcher⁷.

Results

Summary of Included Papers

A total of 1331 articles were initially retrieved from databases and forward and backward tracking. Following removal of duplicates, 1182 articles remained. After full-text screening, 21 articles remained for inclusion (see Figure 1 for full details).

The majority of studies (n=17) carried out interviews or online surveys. Twelve studies collated data via semi-structured interviews only, two from semi-structured interviews and focus group interviews, one from focus groups only, and two from online surveys. These studies contained a total of 331 participants (Range = 4-31; Mean = 19.47). Data from non-autistic individuals, other experiences, or quantitative methods was removed from the review (n=7). Participants ranged in age from 16-62 years. Data regarding gender was available for 313 of the participants: 170 males, 126 females, and 17 'other' (for example, non-binary or genderqueer).

The four remaining studies used textual information: magazines run by and produced by autistic adults (n=2); an online autism forum (n=1); various websites written by autistic individuals (meaning there was not specific participant information; n=1).

The majority of studies utilised thematic analysis (n=12), grounded theory, content analysis, discourse analysis, interpretative phenomenological

⁷ Professor Nigel Beail (Consultant Clinical Psychologist): Primary Supervisor.

analysis and another phenomenological approach was also utilised (see Table 1 for a summary of main characteristics for each study).

Quality Appraisal Results

Table 1 also shows the relevant scores and categories for each study (as constructed by the lead researcher; see Appendix B). Appendix C shows all item scores of the quality assessment for each included study. Overall, all studies had scores higher than 5/10, indicating all studies were of “fair”, “good”, or “excellent” quality. The majority were of “good” quality (n=11), eight were “fair”, and two “excellent”. Most studies lost points for limited information on reflexivity. Some lost points for not explicitly stating ethical approval or epistemological perspective, as well as lacking explicit information to ascertain relevant participant contributions via quotes.

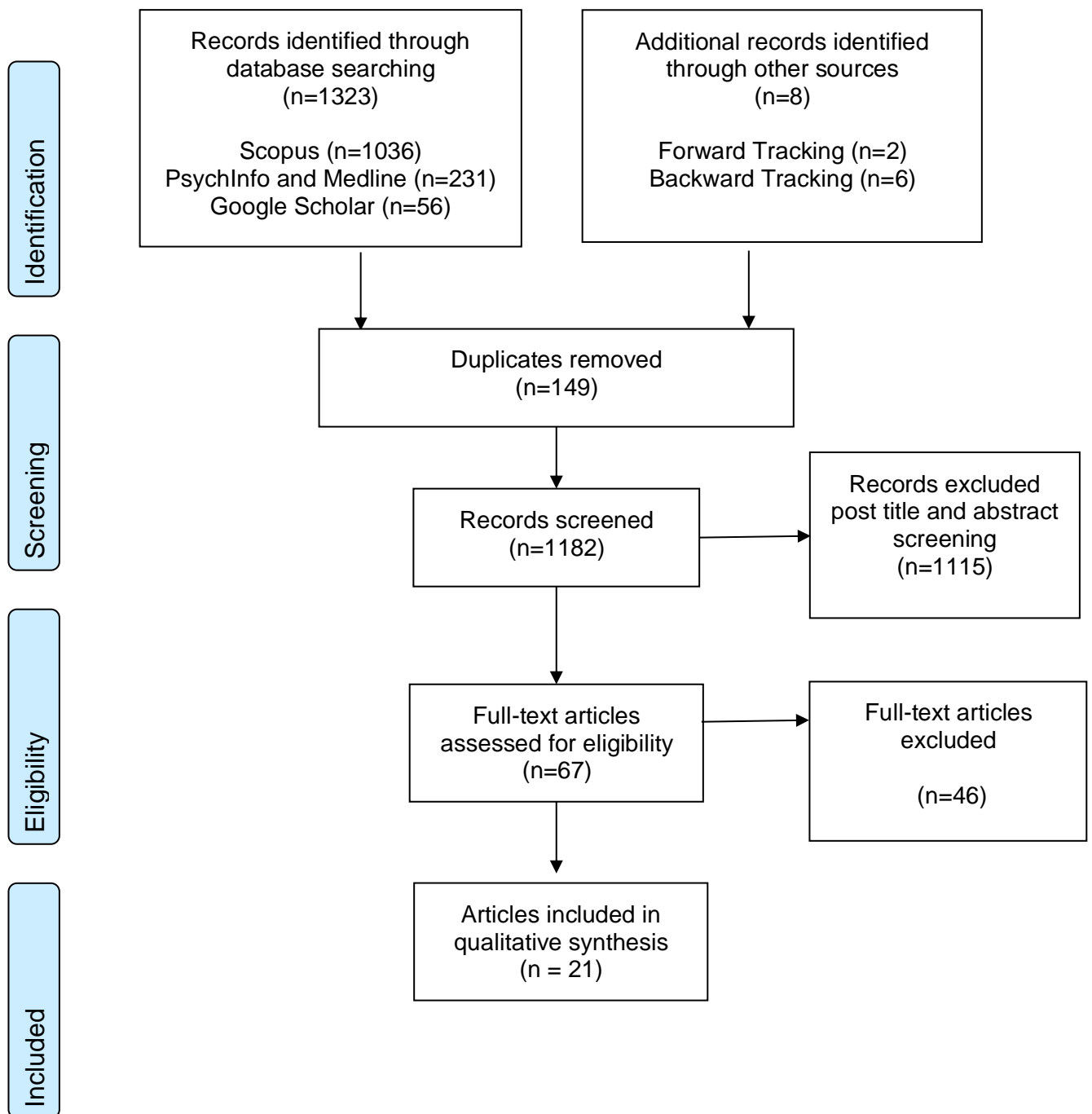


Figure 1. PRISMA Diagram showing search strategy; adapted from Moher et al.

(2009)

Table 1
Summary of Study Characteristics

| Authors (Year) | Country | Participant Characteristics | Recruitment | Data Collection & Methodology | Key Findings & Themes | Quality Score & Category |
|-------------------------------|---------|---|---|--|---|--------------------------------|
| Jones & Meldal (2001) | UK | N = 5 Websites of autistic individuals (very likely adults due to date and use of internet needed) discussing social relationships | Internet searches for websites. | Collated textual information Grounded Theory | Awareness of communication/ comprehension difficulties; A desire for relationships; Attempts to fit in using role-play; A supportive community; The benefits of the internet. | 6/10 Fair |
| Sperry & Mesibov (2005) | USA | N = 18 Aged 22-49 17 Males 1 Female | Social groups for autistic adults. | Focus Group Interviewing Content Analysis | Developing and maintaining personal relationships; Appropriate behaviour around members of opposite sex; Personal perspectives on having autism. | 5/10 Fair |
| Müller et al. (2008)* | USA | N = 18 Aged 18-62 5 Females 13 Males | Via telephone calls, personal contacts, support groups for ASCa adults and parents within San Francisco Bay Area. | Semi-Structured Interviews TA _b | Social experiences: Isolation; Difficulty initiating; communication challenges; longing for intimacy; desire to contribute; effort to develop social awareness. Recommendations for social supports: external; communication; self-initiated; attitudinal. | 6/10 Fair |
| Haertl et al. (2013) | USA | N = 24 Initial interviews with participants aged 27-55; 3 females, 3 males | Local ASC support groups. | Semi-Structured Interviews; Four Focus Group Interviews | Socialisation versus isolation. Occupational participation: Play/Leisure; Social participation. | 7/10 Good |

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|--|---------|--|---|--|---|----------------|
| | | | | Phenomenologic al approach with inductive and deductive analysis | | |
| Bertilsson Rosqvist (2014) | Sweden | N = Unknown Articles/text by autistic adults | Text published in the Empowerment magazine (2002- 2009). | Collated textual information Discourse Analysis | Meanings of autistic sexuality; Sexual difference; Whose Problem is it?; Important to inform properly; Becoming a couple; Becoming an Autistic couple. | 6/10 Fair |
| Barnett & Maticka- Tyndale (2015) | USA | N = 24 Aged 18-61 13 Females 6 Males 5 Genderqueer or Androgynous | Announcements on websites and Listervs for the autistic community. | Semi-Structured Interviews TA | Common concerns: Courtship; Sensory dysregulation; Inadequate sex education. Shared strategies for success. | 7.5/10 Good |
| Van Hees et al. (2015)* | Belgium | N = 23 Aged 18-25 6 Females 17 Males | Via Flemish user organisation for ASC, two counselling services for ASC and three Disability Offices attached to higher education institutes. | Semi-Structured Interviews Grounded Theory | Exhausting but necessary social contacts; Striving hard to fit in; Difficulties managing social demands; Awareness of social problems; Doubts about disclosure; | 7.5/10 Good |
| Hannah & Stagg (2016)** | UK | N = 4 Aged 18-25 2 Males | Volunteers from within studies larger quantitative section. | Semi-Structured Interviews | Dissatisfaction with sex education in school; Sexuality; | 7/10 Good |

| | | | | | | |
|----------------------------|---------|---|---|--|--|-------------------|
| | | 2 Females | | TA | Social difficulties; Negative experiences; Understanding others. | |
| Milton & Sims (2016) | UK | N = 361 78 Articles; 81 Letters to Editor; 37 Reviews; 121 Pen-pal entries; 44 announcements All by autistic adults | 21 Editions (April 2008-April 2014) of Asperger United From NAS information service. | Collated textual information TA | Meeting personal needs; Living with the consequences of an “othered” identity; Connection and recognition; Relationships and advocacy. | 9/10 Excellent |
| Bailey et al. (2019)*** | USA | N = 20 Aged 18+ (Mean age = 22.9) 14 Males 5 Females 1 Non-Binary/Genderqueer | Via disability resource centres at degree-granting colleges and Universities in Michigan. | Semi-Structured Interviews TA | Difficulty navigating a new social environment; Struggle to make social connections; Trade-offs with academics; Opportunity to develop meaningful social connections; Friends as a significant source of social support. | 5.5/10 Fair |
| Cheak-Zamora et al. (2019) | USA | N = 27 Aged 16-25 20 Males 7 Females | Via ASC treatment and support agencies in three Midwest U.S cities. | Semi-Structured Interviews TA | Interest in relationships; Ideal partners; Realities of adolescent and young adult relationships; Advice about sex and relationships. | 7/10 Good |
| Elmose (2019) | Denmark | N = 25 Aged 18+ 18 Males 7 Females | Autistic network groups from Danish organisation for autistic adults. | Focus Group & Semi-Structured Interviews TA | Being autistic as a frame of reference; Discrepancies in relationships; Ease of interaction. | 8/10 Good |

| | | | | | | |
|---------------------------|-----|---|--|---|---|----------------|
| Forster & Pearson (2019) | UK | N = 5 Aged 22-25 3 Males 2 Females | Opportunity sampling via personal networks and online platforms (social media). | Semi-Structured Interviews IPA _c | Perceptions and “Learning the Formula”; Socialising... “It’s more complicated than that”; “Taking Advantage of You”. | 7.5/10 Good |
| Gurbuz et al. (2019)* *** | UK | N = 26 Aged 18+ (M = 26.35) 14 Male 10 Female 2 Other | Adverts to UK universities, university colleges, UK organisations working with autistic university students, University Disability Services. | Open-ended questions on an online questionnaire TA | Social functioning: social skills; social activities. Awareness of ASC by others. | 6.5/10 Fair |
| Kock et al. (2019) | UK | N = 8 Aged 24-40 All Female | Purposive Sampling from ASC; Diagnostic Clinics; Adverts in the NAS _d newsletter. | Semi-Structured Interviews IPA | Response to diagnosis; Factors influencing dating behaviour; Sex and sexual experiences; Experience of intimate relationships as a person with autism. | 8/10 Good |
| Sedgewick et al. (2019) | UK | N = 19 Aged 20-40 years All Female | Social media and word-of-mouth across UK. | Semi-Structured Interviews TA | Friendships; Romantic relationships; Challenges of relationships. | 7.5/10 Good |
| Sosnowy et al. (2019) | USA | N = 20 Aged 18-29 11 Males 7 Females | Online parent groups, advocacy organisations, service | Semi-Structured Interviews | Navigating social norms; Finding friends who accept their differences; Shared interests. | 7/10 Good |

| | | | | | | |
|--|-----------|--|--|--|--|---------------------|
| | | 2 Nonbinary | organisations, mental healthcare providers, social media in Philadelphia, USA. | Grounded Theory | | |
| Teti et al. (2019)**** | USA | N = 27 Aged 16-25 20 Males 7 Females | Three ASC treatment and services agencies from three cities in Midwest US via flyers | Semi-Structured Interviews TA | Companionship: current friendships. Sexual interest and experience: Relationship interest; Fewer relationship examples. Access to sexual information: Potential access to information. | 6.5/10 Fair |
| Bertilsson Rosqvist & Jackson-Perry (2020) | Sweden | N = 186 discussion posts Made up of 102 contributors | Discussion posts and comments on a Swedish online forum for autistic adults (October 2007- April 2017) | Collated textual information Discourse Analysis | The trouble with autistic sex; Sexual intensity spectrum; Non-normative sexuality; Non-sociable sex. | 6.5/10 Fair |
| Crompton et al. (2020) | UK | N = 12 Aged 21-51 10 Females 2 Males | Online social media; Local autism organisations. | Semi-Structured Interviews TA | Cross-neurotype understanding; Minority status; Belonging. | 8.5/10 Excellent |
| Sala et al. (2020)**** | Australia | N = 57 31 with ASC _a 26 No ASC Aged 19-54 Aged 20-57 10 Male 5 Male 14 Female 20 Female 7 Non-Binary 1 Non-Binary | Snowballing sample via social media advertising on international support groups for individuals with autism. | Online Survey TA _b | Autistic and non-autistic individuals have similar desire for, ways of maintaining ("communication", "sharing", "respect"), and barriers to intimacy ("conflict"). | 8/10 Good |

Unique barriers and concerns for those with ASC: uncertainty and sensory sensitivity.

Note: ^a= Autism Spectrum Condition (formerly known as Autism Spectrum Disorder; American Psychiatric Association, 2013); ^b = Thematic Analysis; ^c = Interpretative Phenomenological Analysis; ^d = National Autistic Society; *aspects of other experiences were investigated; only those related to the social experiences included in review **adults without ASD interviewed and quantitative data collected (data removed from this review) *** quantitative data also collected (removed from review) ****adults without ASD/caregivers interviewed, results analysed separately but included together in write-up where themes were the same (data from no ASD group only removed from review)

Thematic Synthesis

There were 77 codes in the ‘bank of themes’ (Appendix D) and 14 descriptive themes (Appendix E). Analysis gave rise to four superordinate themes, each with several subthemes, as shown in Table 2 below. The themes are not an exhaustive account of participant’s experiences; instead, they give a summary of relevant themes across studies. Each theme is discussed alongside illustrative participant quotes (see Appendix F for additional quotes). Missing data is represented by the use of ‘...’ and additional explanations of points are included within ‘[]’.

Table 2

Superordinate and Subthemes

| Superordinate Themes | Subthemes |
|--------------------------------|--|
| Relational Difficulties | Indirect Communication Difficulties |
| | Maintaining Connections |
| | Sex and Relationship Difficulties |
| Different Needs and Expression | Not Conforming to the Norm |
| | Impact of Being Different |
| Same as Everybody Else | Desire for, and Experiences of Relationships |
| | Positive Impact of Relationships |
| | Strategies for Success |
| What Helps? | Tailored Support and Education |

Relational Difficulties

This superordinate theme reflects participants reports of communication difficulties, in particular non-verbal communication, which impacted relationship building, maintenance, as well as sexual and romantic encounters.

Indirect Communication Difficulties. In all studies participants reported communication difficulties with “*non-verbal language*” (Elmose, 2019, p.12) or social rules “*that others take for granted*” (Jones & Meldal, 2001, p. 38), which typically led to problems forming connections. Those that felt able to initiate interactions struggled to recognise if the situation was going well, or if they were “*doing it properly*” (Forster & Pearson, 2019, p.8). Others felt unable to initiate due to feeling they lacked social skills:

“...You just can’t walk up to a group of people and just start talking with them and expect them to accept you. I’ve seen my mom do it and I don’t know how she does it...I tried doing something like that, I got chewed out so many times.” (Sosnowy et al., 2019, p.47).

Participants expressed a need for certainty and “*predictability*” (Crompton et al., 2020, p.6) which felt hard to achieve during initiation phases of relationships which were often unstructured. Similarly, participants in several studies described how initiation difficulties were heightened during times of change or transition. These difficulties led to participants feeling “*anxious*”, “*embarrassed*”, (Crompton et al., 2020, p.5, p.7), “*overwhelm[ed]*” (Sedgewick et al., 2019, p.119), or “*nervous*” (Hannah & Stagg, 2016, p.3685), in almost all studies. Additionally, these difficulties and uncertainty led to misreading of social situations and/or “*missed opportunities*” (Kock et al., 2019, p.42).

Maintaining Connections. Despite difficulties with initiation, many participants still formed connections. However, in over half of studies,

participants faced difficulties *“maintain[ing]” “close and long-term relationships”* (Jones & Meldal, 2001, p.38). For some, this was not linked to their social skills, but with struggling to get the right level of intimacy. For example, one participant from Müller et al. (2008) described wanting:

“...more...closeness and friendship without getting too close, because I myself have a very limited tolerance of closeness in relationships.” (p.180).

For others, they struggled to know how to deepen a social connection, such as to move from *“acquaintances”* to *“friends”* (Haertl et al., 2013, p.34), or from *“friend zoned”* (Teti et al., 2019, p.16) to dating.

Sex and Relationship Difficulties. In just over half of studies, participants described specific difficulties with initiating romantic or sexual relationships. A participant in Bertilsdotter Rosqvist’s (2014) study summarised this as:

“For many of us who have autism/AS, love and sex does not work that well. The whole dating thing is all about non-verbal cues – the very thing that we have so much difficulty with...How can you see if someone is interested? How do you notice if someone flirts with you? What do you say when you do not like small talk but do not want to scare your date by getting too personal?” (p.358).

In a third of studies, participants reflected on difficulties with maintenance of sexual and romantic relationships. For some, this related to the *“spontaneous”* (Kock et al., 2019, p.44) nature of sex, for others, it was around having *“extreme”* needs or preferences (for example, hyper- or hypo-sensory experiences, or lacking desire for sex versus it being a *“special interest”* (Bertilsdotter Rosqvist & Jackson-Perry, 2020, “Sexual Intensity Spectrum” section)). This ‘extremeness’ created difficulties for some participant’s own sexual experience, such as *“kissing”* or *“touch”* feeling *“physically painful”*

(Barnett & Maticka-Tyndale, 2015, p.174). For others, the extremeness or management of sensory needs created difficulties for their partner.

In a third of studies, participants reported difficulties establishing if someone was trustworthy in a relationship. This resulted in participants becoming “*more careful*” (Hannah & Stagg, 2016, p.3686) or involved in unhealthy relationship dynamics, which they struggled to “*see*” (Cheak-Zamora et al., 2019, p.2610) or struggled to know how to end or “*avoid*” (Sedgewick et al., 2019, p119).

Different Needs and Expression

This superordinate theme reflects how participants expressed feeling different to the majority. Rather than problems being related to participants’ autism it was this minority status that created issues.

Not Conforming to the Norm. In almost all studies participants reported feeling they did not “*fit in*” (Jones & Meldal, 2001, p.37), did “*not conform to the norm*” (Milton & Sims, 2016, p.528) or were in a “*minority*” (Kock et al., 2019, p.44). Contrasting with the superordinate theme above, these studies contained an alternative narrative, that participants simply had a “*different*” (Bertilsson Rosqvist, 2014, p.355) way of relating or behaving, which contrasted with the accepted social and sexual narratives held by the neurotypical⁸ majority. Some participants described such differences being a mutual misunderstanding of between autistic and neurotypical individuals due to differential needs and communication:

⁸ Individual without autism.

“...I have warned him: if I want to be on my own, if I don’t want to talk, it’s not a comment on you – it’s a comment on me needing rest...away from people but...it may be misinterpreted as not wanting to be around or a personal comment on him – and it is not.” (Kock et al., 2019, p.42).

Other studies highlighted participants worked hard to understand neurotypicals, due to neurotypicals being a majority, but feeling neurotypicals did not meet *“halfway”* (Sala et al., 2020, p.362) as they have *“never had to study autistic people in the same way”* (Crompton et al., 2020, p.7).

For others, this narrative was reflected in neurotypical social environments dominating which can *“often [be] too loud/crowded”* (Gurbuz et al., 2019, p.623) and conflict with autistic needs. Additionally, many studies reflected that participants were in a minority for their gender and sexuality identification, as they tended to *“perceive gender differently than a lot of [neurotypical] individuals”* (Barnett & Maticka-Tyndale, 2015, p.173), resulting in a *“higher proportion of transgendered people...and a greater openness to non-heterosexuality”* including *“asexuality”* (Bertilsson Rosqvist, 2014, p.355). Some studies commented that participants, therefore, did not want to conform to societal norms of relationships, such as living together or becoming a *“parent”* (Kock et al., 2019, p.46).

Impact of Being Different. The majority of studies highlighted that it was the reaction to differences that created difficulties, rather than being autistic. Common reactions reported were others *“avoid[ing]”* (Jones & Meldal, 2001, p.38), *“judge[ing]”* (Gurbuz et al., 2019, p.623), dismissing, as well as pressuring to conform. This led to many participants questioning that they or their preferences were the *“problem”* (Bertilsson Rosqvist, 2014, p.357) and instead noticing that a lack of tolerance for difference was the issue:

“When I am in an environment I feel comfortable in, with people who are kind and tolerant, and doing things I enjoy, then I am as happy as the next person. It is when people tell me I should think, speak or behave differently that I start to feel different, upset, isolated and worthless. So surely the problem is a lack of fit with the environment rather than something inside my brain that needs to be fixed?” (Milton & Sims, 2016, p.527).

Within the majority of studies, participants noted that they were very aware of their differences due to these reactions, leading many participants to “*camouflage*”⁹ (Forster & Pearson, 2019, p.8) or ‘*mask*’ (Crompton et al., 2020, p.8). However, in over half of the studies, this had a negative impact, such as giving them in “*constant heart thumping anxiety*” (Sedgewick et al., 2019, p.119), being “*tiring*” (Sosnowy et al., 2019, p. 47), or not feeling “*really ‘me’[them]*” (Van Hees et al., 2015, p.1679) which “*felt like I [they] were being destroyed*” (Jones & Meldal, 2001, p.39) and “*negates the possibility of friendship*” (Milton & Sims, 2016, p.526), as it made relationships feel “*false*” (Elmose, 2019, p.17).

However, not masking and not conforming also led to negative experiences, such as “*bullying*” (Sala et al., 2020, p.362), “*stigma*” (Milton & Sims, 2016, p.526), or victimisation (for example, “*sexual assault, rape, domestic violence, financial fraud*” (Sedgewick et al., 2019, p.119)). As a consequence of bullying, or not fitting in generally, participants reported feeling “*isolated*” (Müller et al., 2008, p.178), “*lonely*” (Haertl et al., 2013, p.34) or having “*low self-esteem and depression*” (Milton & Sims, 2016, p.526),

⁹ Autistic individuals camouflage or mask their symptoms in order to fit in (Lai et al., 2017).

“emotional problems” (Hannah & Stagg, 2016, p.3685). These negative experiences typically compounded individuals’ already high stress, anxiety, and low self-esteem. For some, these experiences led to *“internalised ableism”* (Crompton et al., 2020, p.7) and shame. Participants also reported being later to date, have sex, or have a romantic partner and in over half of studies participants reported lacking or having fewer connections than neurotypical counterparts.

Same as Everybody Else

This superordinate theme reflects how participants strongly desired relationships, had relationship experiences and these experiences had positive effects on participants.

Desire For, and Experiences of Relationships. All studies, except for Gurbuz et al. (2019), had participants comment on their strong desire for connection with others or spoke of pre-existing friendships and/or romantic relationships. Some described relating socially as a *“need”* (Van Hees et al., 2015, p.1679) among their *“highest aims and desires in life”* (Müller et al., 2008, p.185), or as something they *“value...more than everything”* (Sala et al., 2020, p.362). A participant in Bertilsdotter Rosqvist (2014, p.37) explained it was *“a common misconception”* that autistic adults are *“not interested in romantic relationships”*; rather the participant commented they are just as *“interested”*, and another participant in the same study expressed that autism does not impact one’s ability to *“feel emotions or maintain a commitment in a relationship”* (p.358-359). Similarly, a participant in Sperry and Mesibov (2005, p.372) passionately argued that romantic relationships are for everyone:

“I’ve been in dating relationships, so don’t tell me autistic people cannot handle marriage relationships or dating relationships. It’s a matter of choice it

makes me so angry when people say, 'Well normal people can get married and autistic people can't.'"

This narrative, that relationships (romantic, sexual, or otherwise) were for everyone, regardless of diagnosis, was prevalent in just over a third of studies. Several studies supported this narrative by highlighting autistic individuals had friendships or relationships of similar quality to others. For example, a participant in Bertilsdotter Rosqvist and Jackson-Perry (2020) pointed out that *"sex can be at least as good as the sex of NTs [neurotypicals]"* as it *"hardly requires the social genome to have really good sex"* ("Non-sociable sex" section). Others reflected that differences or difficulties in relationships (sexual or otherwise) was something *"everyone"* experienced (Bertilsdotter Rosqvist, 2014, p.359) as *"no one is 'like everyone else'"* (Bertilsdotter Rosqvist & Jackson-Perry, 2020, "Non-normative sex" section). Similarly, although it was acknowledged autistic individuals may be at higher risk of stigma or bullying, some participants argued, this was *"not just [about] autism"*, but similar for any minority or *"vulnerable"* group, such as *"people with anxiety, mental illness, children, the elderly"* (Forster & Pearson, 2019, p.13).

Linked to this narrative (feeling similar to neurotypicals/that differences are ubiquitous) some participants expressed the importance of being treated equally in neuro-mixed interactions ¹⁰, (for example, neurotypicals meeting them *"halfway"* (Sala et al., 2020, p.362)). This desire reflected how participants in around a third of studies described good friendships or relationships as involving reciprocity, evenness, and mutual understanding:

¹⁰ Interactions or relationships between an autistic individual and neurotypical individual.

"I would say that they are willing to go as out of their way for you as you are for them." (Sperry & Mesibov, 2005, p.369).

Several studies highlighted the importance of "*compromise*" (Sperry & Mesibov, 2005, p.369) or "*negotiation*" (Barnett & Maticka-Tyndale, 2015, p.176) to resolve any conflicts or differences that did arise. Similarly, many studies highlighted other qualities of good relationships such as "*trust*", "*safe[ty]*", "*love*", "*empathy*" (Sala et al., 2020, p.361), "*commit[men]t*" (Sedgewick et al., 2019, p.118), "*understanding*" (Elmose, 2019, p.16), "*open[ness]*" (Milton & Sims, 2016, p.529), and "*support*" (Müller et al., 2008, p.186). Additionally, almost all studies focused on the importance of being accepted and allowed to be themselves within relationships. All of these qualities are typically accepted within society as signs of a healthy relationship, supporting the narrative that autistic relationships are similar to neurotypicals.

Positive Impact of Relationships. Almost all studies commented on participants' positive experiences of having connections with others, such as feeling accepted, understood, and that they belong. In many studies, participants reflected that sharing interests or having similarities aided forming friendships, which for some was a new but profoundly positive experience, as it helped them feel understood and connected socially:

"I sat there my mouth agape. I was surrounded by people just like me, who were eager to learn about the things taught in class. That was absolutely beautiful. I did not go to a lecture. I went to a playground. That was really wonderful!" (Van Hees et al., p.1679).

In many studies, participants expressed connecting with other autistic individuals especially facilitated feeling accepted as they felt more able to let their "*guard*" and "*mask down*" (Crompton et al., 2020, p.6), less "*pressure[d]*"

(Forster & Pearson, 2019, p.11), and less “*judge[d]*” (Sosnowy et al., 2019, p.48), which in turn led to being more “*relaxed*” (Crompton et al., 2020, p.6). A participant in Milton and Sims (2016) described being part of an autistic community as:

“When I meet my people, I know, because I feel it. And my people were there at Autscape¹¹ and the whole thing was imbued with love, expressed autistically, but love nonetheless...Autscape has meant I see my differences as part of the differences that make up the whole of humanity and as something to be celebrated, not something I need to get away from...there was no fear or ridicule. I had never before experienced such a feeling of coming home.” (p.529).

Similar, to the above quote, many studies highlighted that when participants met similar individuals to themselves this led to self-acceptance, “*increased confidence*” (Milton & Sims, 2016, p.528), or improved self-esteem. Several studies commented that relationships with others (regardless of neuro-type) made participants “*happy*” and “*excited*” (Crompton et al., 2020, p.8), as they “*enjoy[ed]*” (Kock et al., 2019, p.42), “*love[ed]*” (Cheak-Zamora et al., 2019, p.2610) and “*had fun*” (Teti et al., 2019, p.14) spending time with their connections. Some studies specifically reflected on the positive impact of physical intimacy within relationships:

“I love closeness! And I love sex...spontaneous playful and loving sex is absolutely wonderful!” (Bertilsson Rosqvist & Jackson-Perry, 2020, section “*Non-normative sexuality, paragraph 6*”).

¹¹ A group and conference run by and for autistic adults: <http://www.autscape.org/>
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Several studies reflected on how participants gained “*emotional support*” (Crompton et al., 2020, p.8) from their relationships with others, such as through talking to others or others being aware of, and supporting participants’ needs:

“My friends generally cheer me up when I’m in a bad mood...” (Forster & Pearson, 2019, p.11).

A couple of studies (Sedgewick et al., 2019; Elmore, 2019) also reflected that being in a romantic relationship had additional benefits of increasing social connections with less effort:

“...she [participant’s girlfriend] was very apt at maintaining friends and other relationships, so I kind of had some of her friends as well!” (Elmore, 2019, p.15).

What Helps?

This superordinate theme relates to strategies that participants feel are useful to help them successfully socialise.

Strategies for Success. As mentioned in the above superordinate themes, participants had a desire for relationships, however, due to differences in social communication participants found establishing long-lasting connections difficult at times. Around two thirds of studies reported participants, therefore, trying to learn strategies to adapt and improve connections. For many this involved “*a lot of effort*” (Bailey et al., p.6), “*concentrate[ion]*” (Elmore et al., 2019, p.17), “*strict, conscious practice over the years*” (Forster & Pearson, 2019, p.8), and “*push[ing]*” themselves (Müller et al., 2008, p.181). In almost all studies, this was motivated by self-awareness of communication difficulties and differences, such as from others “*reaction[s]*” (Jones & Meldal, 2001, p.38) or feeling “*defective*” and a desire to be more “*acceptable to others*” (Milton & Sims, 2016, p.526). For many, learning social skills involved “*watching other*

people and listening to them" (Müller et al., 2008, p.183) in order to better "*read*" (Forster & Pearson, 2019, p.8) others, and then "*adopt*" and "*act in the same way*" (Van Hees et al., 2015, p.1679). Although a useful strategy, this camouflaging to 'fit in', had negative effects on participants as mentioned in the "Impact of Being Different" subtheme. Several studies referred to how, as an alternative to masking, "*self-understanding*" was a useful strategy that aided "*relationships*" (Sala et al., 2020, p.361), often prompted from receiving their diagnosis. Similarly, participants found self-care after socialising useful, such as having a rest or letting their "*brain switch off a bit*" (Crompton et al., 2020, p.6). This strategy also helped manage sexual relationships:

" We had made plans to have sex that night... but I was so wound up and overstimulated from the day that I couldn't even fathom sex at that moment. I just wanted to be left alone for a bit. An hour later, my wife started to slowly touch and caress me, and that helped me to get into the mood." (Barnett & Maticka-Tyndale, 2015, p.176).

Difficulties in sexual relationships due to sensory differences were also managed by some participants through "*alternative*" strategies (for example, using latex gloves (Barnett & Maticka-Tyndale, 2015, p.176)). Some participants reported "*regulat[ing] interaction*" or agreeing to "*meet at certain, specific times*" (Bertilsdotter Rosqvist, 2014, p.361) were also useful strategies for maintaining romantic relationships.

Similarly, some studies reported the importance of being "*prepare[d]*" (Gurbuz et al., 2019, p.623) for social contact or attending structured groups and activities as they provided socialising "*without pressure to communicate verbally*" (Elmose et al., 2019, p.15) or gave a "*minimal framework*" (Müller et al., 2008, p.182) which could be built from. "*Communicating explicitly, in plain*

language” (Sala et al., 2020, p.360) was also preferred by participants as this reduced uncertainty and increased understanding (this was reported to be especially helpful for sexual relationships (Barnett & Maticka-Tyndale, 2015)). Similarly, participants reported preferring “*seeing one or two people at a time*” (Sedgewick et al., 2019, p.11) compared to “*group activities*” (Haertl et al., 2013, p.33) as this interaction felt easier to read and manage. A few studies reported participants having a preference for alternative forms of communication such as “*online*” (Forster & Pearson, 2019, p.12) or “*write[n]*” (Müller et al., 2008, p.185) for this reason.

Tailored Support and Education. In addition to self-initiated strategies, some studies reported that participants found tailored support from friends or family members useful, either through educating, or attending events together. For example, a participant in Crompton et al. (2020) described attending a group with a friend:

“I can be like ‘what is going on here?’” (p.6).

Around a third of studies highlighted the importance of sex education in particular, however, many noted participants had received limited sex education, such as only focusing on “*reproductive biology*” or implying sex is “*extremely dangerous*” due to “*hellish diseases*” that could be caught (Barnett & Maticka-Tyndale, 2015, p.175). For some this led to misunderstandings, such as not understanding why anyone engaged in sex, until they were later explicitly informed “*it was fun, enjoyable and felt good*” (Barnett & Maticka-Tyndale, 2015, p.175).

Participants commented that sex education was not “*clear enough*” and they “*wanted it to have been explained in more depth*” (Hannah & Stagg, 2016, p.3684-5) with more “*specificity*” (Barnett & Maticka-Tyndale, 2015, p.175).

Participants described wanting more information on “*dirty talk*” (Hannah & Stagg, 2016, p.3685) “*how you [are] supported to feel about sex*” (Barnett & Maticka-Tyndale, 2015, p.175), differences “*between friendships and partnerships*” (Sala et al., 2020, p.363), “*more about...recognising good and bad in relationships in general*” and how relationships “*work or...start*” (Cheak-Zamora et al., 2019, p.2611). A participant in Barnett and Maticka-Tyndale (2015) summarised this as:

“Reasonable education about risks, methods, tools, and diversity in sexual desires. Especially how to help make [sex] not painful, or less painful. When bodies are not reacting right...Using appropriate words; penis, vagina, breasts, testicles, etc. Not kid-words or ‘polite’ words. Education about some alternative or unconventional sexual activities. Education about difference between real life and pornographic fantasies, movie sex, book sex. Education about slang words people use to describe sexual activities, body parts, that get used in invitations for sexual activities.” (p. 175).

The above quote highlights participants’ desire for more explicit and diverse education, covering dating, enjoyment of sex and sexuality, such as giving consideration to transgender and asexuality. Some participants reflected that the lack of information left them feeling less able to make informed decisions about sex so they couldn’t “*say ‘I don’t want to get involved with that’ or ‘Yes, I do’*” (Hannah & Stagg, 2016, p.3685). This is especially important considering the increased reports of bullying and victimisation mentioned in the studies.

Discussion

The aim of this review was to identify, critically review and thematically synthesize the current qualitative literature on autistic adults’ relationships. Four

superordinate themes were established; '*Relational Difficulties*', '*Different Needs and Expression*', '*Same as Everybody Else*', and '*What Helps?*'.

The first superordinate theme '*Relational Difficulties*' largely reflects the diagnostic criteria for autism; that autism involves deficits in social communication and interaction, in particular, indirect and non-verbal communication (American Psychiatric Association, 2013). However, it is of note, some ASC features, such as repetitive behaviours were not observed in the current review. Nonetheless, research suggests that social skills deficits, such as difficulties with non-verbal communication, can lead to problems with initiation and maintenance of relationships (Byers et al., 2013; Riggio, 1992); a link that was found in the review. In turn, this may account for research suggesting that autistic individuals have lower quality relationships (Locke et al., 2010).

The second superordinate theme '*Different Needs and Expression*' suggests an alternative to this social skill 'deficit' narrative; instead suggesting autistic individuals are a minority with significant differences to the neurotypical majority which includes strengths and weaknesses. Robertson (2010) previously suggested that such an alternative narrative of neurodiversity, with unique strengths and difficulties, needs to be adopted within autism. Results from the current review suggest difficulties arise not from being autistic, but rather from issues associated with holding a minority status. For example, participants reported awareness of their differences led to anxiety and uncertainty, resulting in avoidance. Such a pattern of social anxiety leading to heightened self-focus (Hirsch et al., 2003), negative self-judgements (Clark & Wells, 1995; Hackmann et al., 1998), and avoidance, is well established by Cognitive Behavioural Theory (Beck, 1967). It could also partially account for

autistic individuals forming fewer connections or making connections later in life (Howlin & Moss, 2012). However, this theory does not reflect participants experiences fully, such as there being real-life differences in social skills to begin with.

Lacking connections negatively impacts mental health, specifically increasing depression and feelings of loneliness (Field et al., 2001; Leary, 1990); this was also noted in the review and could be a factor for the increased incidence of mental health difficulties, specifically anxiety, in autistic adults (Croen et al., 2015). Additionally, in the current review, a minority status and being different also lead to mutual misunderstandings between neurotypicals and autistic individuals. This supports Milton's (2012) concept of the 'double empathy problem' (DEP); that autism does not involve an empathy deficit but that neurotypicals and autistic individuals similarly struggle to understand one another. Following on from the DEP, it may be that autistic individuals' relationships are only of lower quality in neuro-mixed relationships; this was prevalent in the review where individuals reported increased misunderstandings and difficulties in neuro-mixed relationships compared to autistic-autistic relationships (and is consistent with recent research studies; Morrison et al., 2019).

Additionally, the review found that participants had many experiences of stigma, negative judgements and victimisation, consistent with current literature (Humphrey & Hebron, 2015; Treweek et al., 2018; Weiss & Fardella, 2018). The participants also suffered from the well-established long-term impact of such experiences; mental health difficulties, fewer long-lasting relationships and internalised shame (Ahmed & Braithwaite, 2005; Arseneault, 2017; Wolke & Lereya, 2015). It may be that stigma and victimisation occurring is linked to the

DEP, as such experiences are reported to be more common from neurotypicals; which links with Sasson et al.'s (2017) findings that neurotypical peers tend to make quick, negative judgements of autistic adults. Such judgements appear to contribute to negative stereotyping and stigma of autistic adults (Harnum et al., 2007; Wood & Freeth, 2016).

Experiences of stigma and victimisation in the review may have also been linked to participants reporting higher incidences of gender dysphoria or non-heterosexuality, which is common within current research (George & Stokes, 2018; Glidden et al., 2016). LGBT groups are also more likely to experience victimisation (Government Equalities Office, 2018). However, little research has been conducted into experiences of autistic individuals who also identify with a gender or sexuality minority group, although Hillier et al. (2019) conducted a qualitative study with such a population and found high levels of discrimination.

Many participants in the review reported trying to overcome social differences and their impact via a common coping mechanism of 'masking' to fit in. Although useful, this created difficulties in forming connections that felt true to them or had an impact of social fatigue (such negative consequences have been previously evidenced (Hull et al., 2017)). Current research, and this review, suggest that although individuals with autism experience some degree of social deficits, the impact of being different, stigma, victimisation and the DEP likely play a significant role in compounding any pre-existing social difficulties.

The third superordinate theme, '*Same as Everybody Else*' supports research that suggests it is a misconception that autistic adults do not want relationships, including sexual relationships (Urbano et al., 2013); in almost all studies within this review participants reported wanting connections and having

achieved these to what they felt was a similar quality to neurotypical relationships, despite differences and difficulties. However, it is of note, some participants expressed a preference for fewer connections or a lack of desire sexually. This review, therefore, suggests that autistic individuals might have more 'extremes' of preference (such as lack of desire versus sex or relationships being a special interest). This links with other research into autism that suggests individuals have hyper- and hypo- sensory reactivity, perception, and memory (Elwin et al., 2013; Markram, 2007) and it may be that social or sexual preferences are another example of a hyper- and hypo- expression in autism.

Additionally, expressed within the third superordinate theme was that friendships and relationships had a positive impact on autistic individual's well-being, which is found within the general population (Buhrmester, 1996; Simpson et al., 2007). Linked to the DEP, many participants reported increased feelings of belonging and acceptance within relationships with other autistic individuals, which has also been reported by Sinclair (2010).

The fourth superordinate theme, '*What Helps?*' provides an indication for strategies that support autistic individuals' socialising. Largely these are things that are found to be helpful to autistic individuals in general, such as clear communication, planning, preparation, routine, self-care and structure (National Autistic Society, 2017, 2018). Additionally, the review found that self-acceptance, often through receiving a diagnosis, supported well-being and in turn, socialising, consistent with previous findings (Hearst, 2015; Leedham et al., 2020). Within the review there was a narrative that sex education in particular was limited, as previously found by (Koller, 2000) and that sex

education would benefit from being tailored for autistic adults with increased diversification, consistent with Mehzabin and Stokes (2011).

Summary of Methodological Quality in Studies

Typically, earlier publications (pre 2010) and studies within this review that utilised mixed methodology (for example, Bailey et al., 2019; Gurbuz et al., 2019) were of lower quality. This is likely due to general improvements in research quality over time, as well as having a split, or primarily quantitative focus, resulting in less rigour for the qualitative aspect of research. Studies that were of lower quality typically contributed less to codes; for example, Sperry and Mesibov (2005) contributed the least to codes, whereas higher quality studies such as Milton and Sims (2016) and Kock et al. (2019) contributed to the most codes. It is also of note some of the higher quality papers such as Milton and Sims (2016) and Crompton et al., (2020) had authors that were autistic.

Almost all of the included studies had congruity between their research method and methods of data collection, analysis and conclusions drawn; increasing the readers confidence in the rigour of the method and analysis. Most studies provided sufficient illustrative quotes from a variety of participants. However, some studies did not provide enough information to determine the level of contributions from various participants or if there were outliers. Most studies were ethically sound; however, a couple of studies did not explicitly gain ethical approval; rather they referred to and explained how they addressed ethical issues. One study (Elmose, 2019) did not seek ethical approval, which although in line with their country's guidance, is not in line with UK guidance. Most studies did not sufficiently state their epistemological orientation or consider and make use of reflexivity, which would have given a better

understanding of the researchers' influences and biases, in turn increasing transparency (Spencer & Ritchie, 2011).

Clinical Implications

The review highlights the detrimental impact of a 'deficit' narrative and supports the DEP. It would, therefore, be useful for services (i.e. education, general health services, autism services) that may interact with autistic individuals to adopt a narrative of 'difference' rather than 'deficit' or 'disorder' in relation to autistic adults. In order to support adoption of this narrative it would be useful for services and education facilities to provide psychoeducation on neurodiversity to both autistic and neurotypical individuals.

Additionally, in line with requests from autistic individuals within the review around sex and relationship education, it would be useful for schools to provide psychoeducation on gender identification, sexual development, and features of healthy relationships. This also highlights the importance of working collaboratively with autistic adults (i.e. *"nothing about me without me"*; Zelmer, 2019, Title of Article).

When working with autistic adults it may be helpful to provide psychoeducation on the DEP and how negative judgements from others can lead to internalised shame. This could possibly negate some of the negative internalisation participants reported in the review, as well as normalise and validate differences, in order to facilitate self-acceptance. Similarly, signposting or supporting the development of autistic adult social groups could facilitate a safe, autistic friendly space to develop connections and acceptance.

In terms of preventative implications, it might be helpful to consider improved access to psychological support for children and adolescents that experience bullying. Similarly, improved access and tailored mental health

support for autistic individuals would be useful, such as clinicians utilising clearer communication, providing structure, and the option for technological or alternative methods of communication during interactions.

Limitations and Future Research Directions

The review excluded grey literature and articles not published in English (to ensure some level of rigour in the research reviewed and a practical limitation due to language barriers). However, this introduces some potential bias (for example, cultural). Future research may benefit from including grey literature and articles published in any language.

In general, the review utilised wide inclusion criteria due to limited research into this area. However, it might be helpful for future research to establish similarities and differences in experiences of particular age groups (for example, young age versus older adults), relationship types (for example, romantic, sexual, or friendship) or neuro-dyads (neuro-mixed versus autistic to autistic relationships).

The review excluded articles focusing on relationships formed explicitly at work (to distinguish between social and work relationships). However, individuals do form relationships through work that exist outside of work. Future research, therefore, may wish to explore differences in socialising across various contexts.

The review supported previous research regarding higher incidences of gender dysphoria and non-heterosexual identification in autistic adults. Further research into the experiences and outcomes of autistic adults who also experience another minority status may be useful.

The review followed Thomas and Harden's (2008) guidance on thematic synthesis thoroughly, and for transparency, stages of the process are included

in the Appendices. However, no audit was completed which would increase the reader's confidence in how well the process was completed.

Conclusions

The review suggests moving from a 'deficit' narrative to a 'difference' narrative within autism. The results highlighted difficulties with socialising were not from being autistic, but rather from issues associated with holding a minority status, such as awareness of difference, the 'double empathy problem', experiences of victimisation, anxiety and internalised shame. Development of fewer, or later, connections with others was a consequence of such issues and negatively impacted participants' mental health. Nonetheless, autistic adults had a strong desire for, and successfully formed, relationships despite these differences and difficulties which positively impacted wellbeing. Strategies such as self-acceptance, self-care, planning and structure were beneficial in supporting relationship development.

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Appendices

Appendix A: Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research

Appendix B: Quality Categories

Appendix C: Critical Appraisal Scores

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Appendix A: Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research

JBI Critical Appraisal Checklist for Qualitative Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

| | Yes | No | Unclear | Not applicable |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. Is there congruity between the stated philosophical perspective and the research methodology? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Is there congruity between the research methodology and the research question or objectives? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Is there congruity between the research methodology and the methods used to collect data? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Is there congruity between the research methodology and the representation and analysis of data? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Is there congruity between the research methodology and the interpretation of results? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Is there a statement locating the researcher culturally or theoretically? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Is the influence of the researcher on the research, and vice-versa, addressed? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Are participants, and their voices, adequately represented? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

Appendix B: Quality Categories

| Category | Score Range on JBI |
|-----------|--------------------|
| Excellent | 8.5-10 |
| Good | 7-8 |
| Fair | 5-6.5 |
| Poor | <5 |

Appendix C: Critical Appraisal Scores

JBI (2017) Critical Appraisal Checklist for Qualitative Research

| Authors (Year) | Item 1 | Item 2 | Item 3 | Item 4 | Item 5 | Item 6 | Item 7 | Item 8 | Item 9 | Item 10 | Total |
|--|--------|--------|--------|--------|--------|--------|--------|--------|--------|---------|--------|
| Jones & Meldal (2001) | No | Yes | Yes | Yes | Yes | No | No | Yes | No | Yes | 6/10 |
| Sperry & Mesibov (2005) | No | UC | Yes | Yes | Yes | No | No | No | UC | Yes | 5/10 |
| Müller et al. (2008) | No | Yes | Yes | Yes | Yes | No | No | UC | UC | Yes | 6/10 |
| Haertl et al. (2013) | Yes | Yes | Yes | Yes | Yes | No | No | No | Yes | Yes | 7/10 |
| Bertilsson Rosqvist (2014) | UC | Yes | Yes | UC | Yes | No | No | Yes | No | Yes | 6/10 |
| Barnett & Maticka- Tyndale (2015) | UC | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | 7.5/10 |

| | | | | | | | | | | | |
|-------------------------------------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|--------|
| Van Hees et al. (2015) | UC | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | 7.5/10 |
| Hannah & Stagg (2016) | No | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | 7/10 |
| Milton & Sims (2016) | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | 9/10 |
| Bailey et al. (2019) | No | No | Yes | Yes | Yes | No | No | UC | Yes | Yes | 5.5/10 |
| Cheak-Zamora et al. (2019) | UC | Yes | Yes | Yes | Yes | No | No | Yes | UC | Yes | 7/10 |
| Elmose (2019) | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | 8/10 |
| Forster & Pearson (2019) | Yes | Yes | Yes | Yes | Yes | No | No | UC | Yes | Yes | 7.5/10 |
| Gurbuz et al. (2019) | No | UC | Yes | Yes | Yes | No | No | Yes | Yes | Yes | 6.5/10 |
| Kock et al. (2019) | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | 8/10 |
| Sedgewick et al. (2019) | No | Yes | Yes | Yes | Yes | Yes | No | UC | Yes | Yes | 7.5/10 |

| | | | | | | | | | | | |
|---|-----|-----|-----|-----|-----|-----|----|-----|-----|-----|--------|
| Sosnowy et al. (2019) | Yes | UC | Yes | Yes | Yes | No | No | UC | Yes | Yes | 7/10 |
| Teti et al. (2019) | No | Yes | Yes | Yes | Yes | No | No | Yes | UC | Yes | 6.5/10 |
| Bertilsson Rosqvist & Jackson-Perry (2020) | UC | UC | Yes | Yes | Yes | No | No | Yes | UC | Yes | 6.5/10 |
| Crompton et al. (2020) | UC | Yes | Yes | Yes | Yes | Yes | No | UC | Yes | Yes | 8.5/10 |
| Sala et al. (2020) | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | 8/10 |

Note. Yes = 1, No = 0, Unclear (UC) = 0.5, N/A = 0

Appendix D: Bank of Codes

| |
|--|
| Bank of Codes |
| Insight into Social / Communication Difficulties |
| Not Understanding Others (esp. NT's) |
| Social & Communication Difficulties (incl. Social Rules) (GENERAL) |
| Initiation / Joining In Difficulties (GENERAL) |
| Difficulties with Non-Verbal Communication |
| Mis-reading/Missing Cues & Situations |
| Maintaining / Deepening Relationships (non-romantic) Uncertainty & Difficulties |
| Unstructured Interaction (e.g. Small Talk) / Others Being Unpredictable Hard |
| Changes / Transitions Hard |
| Social Pressure / Expectations |
| Interaction / Intimacy Level In Extremes (wanting lots or minimal) |
| Not Fitting In / Not Conforming |
| Differences (not worse) |
| Neuromixed couple / people; struggle with differences |
| Non-ASD Norms Dominating |
| Wanting to be treated same as NT's (respect, not made to change, or equal efforts to adapt/understand) |
| All Different; Normal As Relative |
| Relationships, Sex, Feelings (and difficulties) For Everyone/Normal |
| Desire for Relationships / Connection |
| Desire for Contribution & Community |
| Having Friends |
| Having / Had Partner |
| Being in a Relationship (Being in Love)- Enjoyable, Positive, Giving more social ops |
| Structured Activities= positive, easier, giving community |
| Being Part of Group / Social Network = positive, acceptance |
| Having Friends / Connection - Positive for self-esteem/mood, enjoyable, |
| Shared Diagnosis = Community, Belonging, Social Opportunities |
| Similarities & Sharing Interest Positive for Developing Connection |
| Importance of Self-Acceptance & Understanding |
| Importance of Being Accepted, Understood, Allowed to Be Self |

| |
|---|
| Importance of Safety |
| Comprising / Negotiating / Resolving |
| Good friendship/relationship= accepting, respectful |
| Importance of Reciprocity & Evenness & Mutual Understanding/Effort |
| Good Relationship (romantic/other) Foundations = love, understanding, open |
| Importance of Commitment In Relationship |
| Structure, Focus, & Routine Helps |
| Planning & Preparation Helps Socialising/Sex/Relationships |
| Groups harder, 1:1 / smaller groups easier |
| Importance of Showing Interest In Others |
| Technological / Indirect Communication (positive) |
| Managing Social Difficulties / Burnout (e.g. alone time) |
| Social Support From Others Helpful |
| Need & Preference for Clear / Explicit Communication |
| Importance of Support From Self (Not Others) |
| Observing & Copying Others |
| Trying to Learn / Improve Social Skills |
| Diagnosis Positive for Understanding |
| Camouflaging / Trying to Fit In |
| Negative Reaction from Others or Impact to Self Giving Insight/Prompt to Change |
| Fitting In = Feeling False / Negative Impact |
| Social Difficulties = Stress, Anxiety, Insecure, Distress |
| Social Difficulties = Isolation & Loneliness (not fitting in) |
| Lacking (or less) connections/friendships/relationship experience |
| Bad Experiences = Anxiety & Avoidance |
| Uncertainty & Social Difficulties = Cautious Or Avoiding |
| Abuse, Bullying, Victimisation |
| Others Avoid / Dismiss / Judge |
| Fear of Stigma / Judgment / Disclosure / Misunderstanding |
| Misunderstood by Others |
| Relationships / Friendships Hard / Lot of Energy / Exhausting |

| |
|--|
| Importance of Trust & Struggling to know who is trustworthy |
| Dating & Sex Communication/Social Rules Uncertainty & Difficulty |
| Unhealthy Relationships |
| Initiating Sex / Dating Uncertainty & Difficulty |
| Maintaining Romantic Relationships Uncertainty & Difficulty |
| Later to date, have sex, or have a partner (improvements over time) |
| Autism & Sex Differences; Physical & Sensory Hyper / Hypo |
| Asexual / lack of desire for relationships or sex |
| Autism, Gender & Sexuality Differences (Incl. Asexual, transgender etc) |
| Sex & Sexuality Difficulties |
| Importance Of Tailored Education/Advice on Sex & Dating (incl. 'Good Relationships') |
| Managing Difficulties / Supports for Relationships & Sex (Communication, Limiting Interaction, Sensory Supports) |
| Limited Sex Education / Sexual Exploration Ignored Or Discouraged |
| Sex (esp in a relationship) Positive for Well-Being / Connection |
| Exploring, Desire for, Enjoying Physical Intimacy / Touch |
| Not Wanting to Follow Relationship Norms (e.g. children, living together) |

Appendix E: Summary of Descriptive Themes

1. Social and Communication Difficulties

This was the most common theme; it includes codes around difficulties such as with non-verbal understanding and unstructured activity.

2. Initiation Difficulties

Studies participants' often spoke of struggling knowing how to initiate a friendship or dating or missing opportunities due to their difficulties.

3. Maintenance Difficulties

Where some participants had managed to form friendships and relationships, some then struggled to know how to maintain or deepen these relationships.

4. Negative Impact of Social Difficulties

Many codes related to the negative impact of social difficulties, such as mental health difficulties, social anxiety, loneliness or isolation.

5. What Helps Socialising?

Many of the participants in the studies were very motivated to form relationships and so tried to learn coping strategies such as camouflaging and observing others.

6. Negative Impact of Strategies Used

Utilising strategies could impact participants negatively as they felt exhausted or felt they were not being themselves.

7. Social Differences (not difficulties)

Several studies had a narrative around autism not being the problem, but that autistic individuals are different to neurotypicals. Relationships with neurotypicals were typically described as harder than with other autistic adults. There was a narrative that neurotypical expectations and norms dominating and the pressure these caused were more of an issue.

8. Same for Everybody

Participants referred to how they were similar to others in their desire for relationships and not wanting to be treated differently.

9. Desire For, and Having Relationships

Almost all studies referred to the desire participants had for connection and relationships. Many had experiences of these.

10. Positive Impact of Relationships

Many studies spoke of the positives of having connections, such as feeling accepted. They also reflected on aspects that helped gain a positive relationship.

11. What Makes a Good Relationship?

Aspects and qualities of others, or the relationship itself, which would support it being good, were reported by many studies.

12. Autism and Sex Difficulties

Many studies referred to those with autism as experiencing difficulties with sex, often related to having more extreme preferences, for example, hyper or hypo sensory experiences or lacking a desire for sex versus sex being a special interest.

13. Autism and Sex Differences

There was a narrative that those with autism were more likely to have non-conformist gender identity and sexuality.

14. Importance of Tailored Sex Education

Some of the studies highlighted a lack of sex education (formal and informal) and the importance of this being thorough and tailored.

Appendix F: Selection of Additional Illustrative Participant Quotes

| Superordinate Themes | Subthemes | Additional Quotes |
|--------------------------------|-------------------------------------|--|
| Relational Difficulties | Indirect Communication Difficulties | <p><i>"The most difficult thing about this social transition has been getting up the courage to introduce myself. I'm...very shy in general, so that adds another layer of difficulty."</i> (Bailey et al., 2019, p. 5).</p> <p><i>"One day I made eye contact with her, and it seemed like she might have been interested in being friendly, but I didn't know how to deal with it..."</i> (Müller et al., 2008, p.180).</p> |
| | Sex and Relationship Difficulties | <p><i>"...we aspies are bad at being 'moderate'. And when it comes to sex, this may either be great for the partner (if he/she finds the 'right' aspie), or on the contrary, be an insurmountable problem."</i> (Bertilsdotter Rosqvist & Jackson-Perry, 2020, "Sexual Intensity Spectrum" section).</p> <p><i>"...skin against skin contact could be quite unpleasant...sometimes trying to put a sheet or pillow between me and the other person...gets kind of interpreted as a sort of rejection."</i> (Kock et al., 2019, p.44).</p> |
| Different Needs and Expression | Impact of Being Different | <p><i>"I do not easily tell people that I have autism because of the reaction I usually get when I actually do. People who say: 'No, that can't be right, you don't have autism.'" (Van Hees et al., 2015, p.1680).</i></p> <p><i>"...People expect you to know stuff about their life, and that means having to concentrate in conversations and really care about what they say."</i> (Forster & Pearson, 2019, p.10).</p> <p><i>"...what's holding myself back from intimacy isn't so much being neurodiverse but how society feels about neurodiverse people..."</i> (Sala et al., 2020, p.362).</p> |

| | | |
|---------------------------|---|---|
| Same as Everybody Else | Desire for and Experiences of Relationships | <p><i>“...It must also be OK to live alone without a partner if one wants it that way and not have to have relatives and others around harping, ‘Shouldn’t you find somebody soon?’” (Bertilsdotter Rosqvist, 2014, p.358).</i></p> <p><i>“It is easy to think of different sexual expressions as problems- but who ever said that everything that is different has to be a problem? ...Is this behaviour really a problem – and if so, whose problem is it?” (Bertilsdotter Rosqvist, 2014 p.357).</i></p> <p><i>“work[ing] hard at communicating and trying to build up your understanding of your partner’s perspective...to help the relationships succeed.” (Sala et al., 2020, p.361).</i></p> |
| | Positive Impact of Relationships | <p><i>“I didn’t have that many friends, and I was really lonely. And when I met my roommate it made a big difference in my life, because I finally connected with someone....I finally found somebody like me.” (Haert et al., 2013, p.34).</i></p> <p><i>“...you get to share [activities] with that one another and it means that the world is twice as big, twice as colourful, twice as detailed...” (Kock et al., 2019, p.46).</i></p> <p><i>“I love hugs and hug people as much as I can...I like holding hand with my friends, especially in strange places or when I am stressed.” (Barnett & Maticka-Tyndale, 2015, p.176).</i></p> <p><i>“I can tell them anything.” (Sedgewick et al., 2019, p.117).</i></p> <p><i>“Like a family.” (Teti et al., 2019, p.14).</i></p> |
| What Helps? | Strategies for Success | <p><i>“I got the diagnosis and it’s like...I don’t have to be turned on all the time. It is ok to say I’m overwhelmed...” (Kock et al., 2019, p.42).</i></p> |
| | Tailored Support and Education | <p><i>“The autistic spectrum is so wide that I know many of you will be reading this thinking, ‘Oh, I don’t need social skills training’, but some people do, especially about bullying.” (p.528).</i></p> |

*“Sex education is really important, you know? I hear nothing about sex, but I was really concerned at a lot of the noises I heard in the dorms...I thought people were hurt.”
(p.2610).*

Section Two: Research Report

Lived Experiences of Autistic Mothers: An Interpretative Phenomenological Analysis

Abstract

Objectives

Parenthood is associated with positive and negative experiences (for example, connection and increased stress). Autistic parents may experience unique strengths and challenges. This study sought to better understand the experience of autistic parents, such as parent-child attachment, parental stress, and parenting related interactions with others (including services).

Design and Methods

A qualitative design of Interpretative Phenomenological Analysis was utilised. Nine autistic mothers to children (aged 5-15 years) participated in semi-structured interviews.

Results

Four superordinate themes were found; ‘*We’re all different*’; *Autism Impacts Parenting*’; *Battle for the Right Support*’; *Development and Acceptance*’; and *The Ups and Downs of Parenting*’.

Conclusions

Autistic parents have similar parenting experiences to non-autistic parents (for example, enjoyment, connection, stress). Autistic parents also experience unique strengths and challenges. Misunderstandings and judgements from professionals were particularly challenging. Participants’ children typically also had ASC and this shared diagnosis led to increased judgements from others but also strengthened the parent-child bond.

Practitioner Points

- Child and adult autism services should consider the family unit as a whole, including the impact of both parent and child having ASC.

- Increased understanding within general healthcare services is needed on masking, sensory sensitivities in pregnancy, the 'double empathy problem', and how autistic adults are able to form and maintain relationships, including having families and being good parents.
- Future research could focus on the differential experiences of fathers and various dyads of autistic and typically developing parents and children.

Keywords

Autism; ASC; Parent; Interpretative Phenomenological Analysis; Qualitative Research.

Introduction

Autism Spectrum Condition¹ (ASC) is a life-long neurodevelopmental condition characterised by difficulties in social communication and social interaction, as well as a presence of restricted and repetitive behaviours and sensory sensitivities (American Psychiatric Association, 2013).

Research on autistic² individuals has predominately focused on children, with limited work exploring the lives of autistic adults (Howlin et al., 2015). This is an omission, as it is well evidenced that this population experience poorer outcomes, such as high rates of comorbid mental health conditions (Buck et al., 2014; Croen et al., 2015; Gillott & Standen, 2007; Hofvander et al., 2009; Joshi et al., 2013; Lever & Geurts, 2016; Maddox & White, 2015), lower quality of life (Van Heijst & Geurts, 2015), reduced social resources (Autism Speaks, 2017), and increased number of suicide attempts (Cassidy & Rodgers, 2017; Croen et al., 2015) compared to neurotypicals³. Despite awareness of these poorer outcomes, little research has focused on the reasons for them (Howlin et al., 2015) and autistic adults feel more research is needed on factors impacting their day-to-day lives (Pellicano et al., 2014). Given the impact of social factors on mental health and quality of life (World Health Organization & the Calouste Gulbenkian Foundation, 2014), it would be valuable to better understand the social world of autistic adults.

¹ Autistic individuals prefer the term ASC compared to Autism Spectrum Disorder, which is the diagnostic term (Kenny et al., 2016)

² Identity first language (i.e. autistic) has been found to be the preference in the majority of autistic individuals compared with first person language (i.e. person with autism) (Kenny et al., 2015). This language will be used henceforth.

³ Individual without autism.

For many, the social world of adulthood involves becoming a parent. Across many different cultures it has been shown that having a child brings mixed experiences; positive, such as joy, warmth, and connection to another, as well as negative, such as increased stress (Louie et al., 2017). Autistic adults appear to have somewhat differential experiences of some life events with unique strengths and weaknesses compared to neurotypicals (Schuler, 1995; Sinclair, 1998). It is, therefore, possible that autistic adults may have differential strengths and difficulties associated with parenting. For example, it is estimated that parents, particularly mothers, are more likely to experience depression compared to non-parents (Smith, 2004a). Considering this, and the aforementioned research on comorbid mental health in autistic adults, autistic parents may experience increased challenges in managing mental health difficulties whilst parenting. In terms of strengths, employment research indicates autistic adults show higher standards of work compared to neurotypical counterparts through increased attention to detail and strong work values (Lorenz et al., 2016). It may be that they show this same level of attention and dedication to parenting.

Attachment theory (Bowlby, 1958) describes a positive, reciprocal relationship between parent and child as the building blocks for child development. Children with secure attachment (Ainsworth et al., 1978) have increased emotional intelligence, social skills, and reduced mental health difficulties; this positive impact carries through to adulthood (Howe, 2011). However, Dissanayake et al. (2019) notes that many autistic traits relate to social difficulties which could impact the parent-child relationship. It would, therefore, be valuable to gain better understanding of not only how autistic

parents experience parenthood, but also their views on how their autism may affect their relationship with their child, if at all. This could provide insights into the application of attachment theory in relation to autistic parenting and possibly have implications for family or systemic interventions.

Drawing on literature from another developmental disability in adulthood, Kaspar and Kroese (2017) found that adults with learning disabilities felt their parenting experience in terms of attachment was the “*same as anybody else*” (p.112), but stigma they faced from others, including services, created difficulty. It is, therefore, important to not only better understand autistic parents’ experiences in terms of parental stress and attachment, but also to consider their experiences of interaction with others, such as services. This would aid consideration of how best to tailor support for autistic parents and their families.

To date (April 2020), a scoping search of the literature revealed there are only seven studies related to autistic parenting. Five of these utilised quantitative designs. Lau and Peterson (2011) investigated the effect of autism on parenthood satisfaction and found no effect. Nonetheless, it is possible there are qualitative differences between autistic adults and neurotypical individuals’ parenting experiences; indeed, some of the later studies indicate possible differences. Van Steijn et al. (2013) investigated the impact of parental autistic traits⁴ on parenting styles. They found higher maternal autistic traits were linked to a permissive parenting style (responsive, but less boundaried) towards their typically developing child, but not to their autistic child. Lau et al. (2016)

⁴ Little demographic information was given regarding the parents; the study did not appear to check if parents have an official autism diagnosis, therefore some may have been diagnosed and some parents may have been neurotypical. Autistic traits were measured by the Autism Spectrum Quotient (Baron-Cohen et al., 2001)

found autistic fathers had lower parenting efficacy compared to mothers with ASC and neurotypical parents without ASC. Dissanayake et al. (2019) conducted a study into parenting needs of those with high versus low autistic traits⁵ and found higher autistic traits were associated with parenting difficulties when parenting their typically developing child. However, all participants also had an autistic child and they did not include these children in the study. Pohl et al. (2020) explored differences between autistic mothers and mothers without ASC; they found autistic mothers were more likely to experience mental ill-health and greater parenting difficulties (such as feeling misunderstood by professionals, struggling with domestic responsibility).

Two studies utilised qualitative approaches: Prince (2010) explored the researcher's own experience as an autistic parent using narrative ethnography; and Bertilsdotter and Lövgren (2013) completed discourse analysis on magazine articles by autistic adults. Both highlighted some similarities of autistic parenting to neurotypicals, such as bonding and trying to achieve 'good enough' parenting. However, they also implied there are extra stresses for autistic parents; Prince (2010, p.62) stated "*...Even more for mothers like me than those of the "normal" type there are very frightening pitfalls*", and Bertilsdotter and Lövgren (2013) noted some felt being a parent involved struggling to balance their own needs against their child's. Although these provide useful insights, the ethnographic design does not allow for themes to be drawn upon

⁵ N=58; of which four participants self-reported to have ASC. All participants had a child with ASC. Traits were scored using the Autism Quotient (Baron-Cohen et al., 2001).

and the discourse analysis included views from autistic adults generally, rather than specifically from autistic parents.

In conclusion, the current literature is sparse, and has not yet included a qualitative approach that sets out to gain a more in-depth understanding of the lived experience of autistic parents in order to better inform care for them, and their child. Biggerstaff and Thompson (2008) highlight how qualitative methods such as Interpretative Phenomenological Analysis (IPA) lend well to studies attempting to gain such deeper understanding of experiences as it aims to give a voice to the participants (Larkin et al., 2006; Smith, 2004b).

Autistic adults have previously successfully taken part in IPA studies and such studies have revealed nuanced lived experiences (such as support experiences (Griffith et al., 2012); social comparisons (Huws & Jones, 2015); mental health (Maloret & Scott 2018); higher education (MacLeod et al., 2018); development into adulthood (Mattys et al., 2018); stereotypes (Treweek et al., 2018)). Additionally, Howard et al. (2019) and MacLeod (2019) found that IPA is a useful approach for autistic individuals as it allows them to represent themselves in autism research.

The aim of the current study was, therefore, to better understand and identify themes about the experiences of parenting by autistic adults, utilising IPA.

Methodology

Design

A qualitative design; specifically IPA, as outlined by Larkin and Thompson (2012) and Smith et al. (2009) was utilised. This is in keeping with the research aims, in contrast to other qualitative approaches; for example, discourse analysis focuses more closely on the function of language and

grounded theory aims to reach a conceptual theory meaning they are less concerned with the individual lived experiences (Willig, 2008).

Ethics

Ethical approval was obtained via the University of Sheffield Research Ethics Approval system (see Appendix A).

Sample Size and Participants

There is no specifically accepted number of participants for IPA methodology (Pietkiewicz & Smith, 2012), however, some argue that fewer participants is beneficial to allow for sufficient depth and rich analysis (Reid et al., 2005; Pietkiewicz & Smith, 2012).

Nine autistic parents were recruited via purposive sampling, meaning participants self-identified as to whether they meet the study requirements.

Inclusion criteria was:

- Over 18 years of age.
- Formal diagnosis of ASC including variants such as Asperger's syndrome, or high functioning autism.
- Parenting experience.
- Currently a parent to child between 5-15 years of age.

Participants were excluded if they had a comorbid learning disability or were not fluent in English. Participant demographic information was collected during interviews. All participants were female, married and aged between 27 and 44 years (Mean age = 39.5). Seven participants identified as White British, one participant as White Welsh, and one as Mixed race. All participants had further education qualifications with minimum qualification level being NVQ Level 2. Five participants had completed Bachelor's degrees and one a Master's degree. Four participants were self-employed, three were employed,

and two were full-time carers or parents. Six participants had additional neurodevelopmental, mental health or physical health diagnoses, of which three felt these previous diagnoses were incorrect and difficulties were related to their autism. All participants, except one, were recently diagnosed: between 0 and 6 years prior to the study (Mean = 2.6 years). One participant was undergoing assessment for diagnosis and self-identified as autistic.

All participants, except one, co-parented with their married partner who was also the birth or adoptive father for all children. One participant had split from their first child's birth father and co-parented with the biological father and their new married partner. See Table 1 for additional information regarding the participants' children. All names are pseudonyms to protect confidentiality.

Table 1.***Demographic Information Regarding Participant's Children***

| Participant | No. of Children in Total | No. of Children Aged 5-15 Years* | Diagnosed with Autism? | Method of Becoming a Parent | Live with Children Full Time? |
|-------------|--------------------------|----------------------------------|---|-----------------------------|-------------------------------|
| Olivia | 3 | 3 | Yes, for all. | Birth | Yes |
| Ava | 2 | 2 | Yes, for all. | Birth | Yes |
| Sophie | 1 | 1 | Yes. | Birth | Yes |
| Lucy | 5 | 3 | One undergoing assessment; One parent feels they have and may undergo assessment. | Birth | Yes |
| Emily | 2 | 1 | Yes. | Birth | Yes |
| Grace | 1 | 1 | No. | Adopted | Yes |
| Zoe | 3 | 2 | Yes, for all. | Birth | Yes |
| Alice | 1 | 1 | Yes. | Birth | Yes |

| | | | | | |
|------|---|---|--|----------------|-----|
| Leah | 2 | 2 | Yes, for one. One has global developmental delay and developmental trauma. | Adopted, Birth | Yes |
|------|---|---|--|----------------|-----|

Notes: *Exact ages and genders of children are not displayed to protect confidentiality.

Materials

A semi-structured interview schedule was developed based on the study's aims and Smith et al.'s (2009) guidance on IPA (see Table 2). The schedule was adapted or deviated from where appropriate to aid the participant to share their lived experience. Prompts were utilised if the participant required clarity or more information, or if the participant had not covered aspects of a question.

Table 2.

Interview Schedule

| Interview Questions | Prompts |
|--|---|
| 1. When did you first find out you were going to be a parent with X (or first child under 5-15 years)? Can you talk me through this? | <i>How did you feel about the idea of being a parent? What did you hope being a parent would be like? What did you do? Do you think being autistic affected how you felt about or dealt with this news?</i> |
| 2a. What was it like for you when you first started being a parent i.e. when X was a baby? | <i>What thoughts, feelings, emotions did you have? Do you think being autistic affected how you felt about being a parent?</i> |
| 2b. How well did you manage being a new parent? | <i>What did you find easy and difficult? How was it different from what you'd expected? Do you think your autism helped or got in the way of being a parent in the beginning?</i> |
| 3. Can you tell me about your initial relationship with your child/children? | <i>What thoughts, feelings, emotions did you have? What was it like communicating and interacting with your child initially? How connected (or not) did you feel towards your child initially? How well (or otherwise) did they bond with you? What was</i> |

| | |
|--|---|
| | <i>easy or difficult about building an initial relationship? How was this different from what you'd expected? Do you think being autistic affected your initial relationship (positively, negatively, or both)?</i> |
| 4. How has your relationship with X been as s/he has got older? | <i>Has it changed over time? What has impacted the relationship over time? What has been challenging or rewarding? How connected (or not) did you feel towards your child as they got older? What was easy or difficult about building/maintaining a relationship as they got older? How was this different from what you'd expected? How do you think they think of you as their parent? Do you think being autistic has affected your relationship as s/he has got older (positively, negatively, or both)?</i> |
| 5a. What are/were the ups and downs of being a parent to child X? | <i>Were there stressors that you felt were linked to being a parent? Were there any positives that you felt were linked to being a parent? How was this different from what you'd expected? Do you think being autistic has affected the ups and downs?</i> |
| 5b. How did you manage these ups and downs? | <i>Do you think your autism has helped manage or got in the way of this (or both)?</i> |
| 6a. How have your family been with you in relation to parenting X? | <i>Prompts for all parts: How have they reacted, perceived, or treated you? How have they interacted with or communicated with you? Have they been helpful/supportive or difficult and interfering (or both)? Have they made any assumptions about you? Were these assumptions accurate? Do you think being autistic has affected the role others have had in your relationship with X?</i> |
| 6b. Have any support services been involved? If so, how have they been in relation to parenting X? | |
| 6c. How have other people been towards you, this could be others not spoken about in | |

the above, such as friends or people you know?

7. Is there anything else that you have not had the chance to tell me about today that you feel would be important for me to know about your experience of being a parent?

Service User Involvement

Two autistic parents who were not eligible for the study were contacted from their details on Sheffield Autism Research Lab (ShARL⁶). They provided advice on the ethical considerations, participant advert (Appendix B), participant information sheet (Appendix C), and interview schedule. Specifically, they gave feedback on the content and wording, as well as whether there were any relevant questions not addressed. Following feedback, changes were made to the interview schedule, such as providing additional prompts.

Procedure

Participants were recruited from four main sources:

- A ShARL database of potential autistic adult research participants that consented to be contacted about research;
- ShARL's twitter account;
- ShARL's website;
- Local charities.

⁶ <https://autismresearchlab.group.shef.ac.uk/>

Participants on the ShARL database were contacted by email with brief study details, inclusion criteria, and participant information sheet attached. Local charities were given a participant advert to distribute via whichever method was convenient for them. The twitter post, website post and advert to charities gave brief study details and provided potential participants with contact details for the researcher. A participant information sheet and consent form (Appendix D) was then sent to those who were eligible and had contacted the researcher.

Interview arrangements were agreed over email and led by the participant's preference. One interview was conducted at the University of Sheffield Psychology Department, two were conducted at participant homes (see Appendix A for the NHS Home Visit Policy that was followed) and the remaining six were carried out via video calling technology. At the beginning of each interview confidentiality and limits to this (i.e. risk concerns) were explained. The interviews were recorded via an encrypted dictaphone obtained from the University of Sheffield. Interviews lasted between 50 minutes, 35 seconds and one hour 36 minutes, 53 seconds (average interview time: one hour 14 minutes). Participants were debriefed following the end of the interview. Interviews were transcribed by an approved University of Sheffield transcriber.

Data Analysis

Reflexivity. Reflexivity involves an awareness and acknowledgment of the researchers' preconceptions and how these may influence the study (Biggerstaff & Thompson, 2008; Langdridge, 2007). Evidence suggests engaging in reflexivity supports a deeper, more thorough understanding of the data, as well as aiding transparency (Clancy, 2013). It is, therefore, of note that the lead researcher is a white British female in their late twenties, without a diagnosis of ASC. The researcher has a diagnosis of Irlen's Syndrome⁷ and Dyslexia giving some (but very different to ASC) lived experience of sensory and neurodevelopmental differences. The researcher has worked with autistic children and adults in various settings, as well as having studied psychological theories and research into autism. The influence of these experiences, theoretical knowledge and preconceptions were reflected on throughout the study via a reflective log. Field notes were utilised during each stage, including analysis, to ensure transparency, reduce bias, and to make use of personal and professional knowledge (see Appendix E for an example entry).

Coding and Analysis. Analysis was conducted utilising principles outlined by Larkin and Thompson (2012) and Smith et al. (2009). Transcripts were initially read through with audio recordings and the researcher engaged in "free coding" (responses, thoughts, ideas on patterns, and observation of important descriptions were noted down). Following this, transcripts were read through again with a more structured and organised approach. Notes on concepts, descriptions, and linguistics were made "line by line" on the right-hand side of the transcripts. Parallel to this, the researcher started to consider "interpretative coding" by noting down possible interpretations and meaning on the left-hand side of the transcripts (see Appendix F for an example transcript).

Following this, individual data was organised and summarised into patterns and themes, creating conceptual maps (see Appendix G). Data was then analysed by looking across the transcripts for overlapping patterns and themes, as well as consideration to exceptions and differences in the data. Following this, superordinate and subthemes were developed (see Appendix H for participant contributions to each theme).

Validity and Quality Control

Smith et al. (2009) highlight the importance of following general guidelines (as opposed to more rigid, standard guidance) on ensuring validity and quality control when conducting IPA. In particular, they endorse Yardley's (2000; 2008) four principles: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. The research maintained these principles during the study. For example, an audit of each stage of the analytic process was carried out on three of the transcripts by a supervisor⁸ to ensure transparency and rigour of analysis (Larkin & Thompson, 2012; see Appendix I).

Results

Superordinate and Subthemes

Data analysis gave rise to four superordinate themes, each with several subthemes, as shown in Table 3 below. Each theme is discussed alongside illustrative participant quotes. Missing data is represented by the use of '...' and additional explanations of points are included within '[]'. The themes are not an

⁷ Light and colour perception sensitivity resulting in reading difficulties, migraines, and difficulty adapting to bright or dark environments (Mears, 1980).

⁸ Dr Megan Freeth (Senior Lecturer in Psychology at The University of Sheffield): Primary Supervisor.

exhaustive account of participants' experiences, instead they are an interpretative narrative of several accounts (see Appendix J for additional supporting quotes).

Table 3.

Superordinate Themes and Subthemes

| Superordinate Themes | Subthemes |
|---|--|
| 1. "We're all different"; Autism Impacts Parenting | 1.1 Shared Diagnoses and Similarities 1.2 An Intrinsic Part of Self for Better or Worse |
| 2. Battle for the Right Support | 2.1 Misunderstood, Judged and Dismissed 2.2 Understanding ASC within the Family Unit |
| 3. Development and Acceptance | 3.1 Diagnosis, Self-Care and Self-Acceptance 3.2 Parenting as Growth and Adaptations |
| 4. The Ups and Downs of Parenting | 4.1 Connection, Enjoyment and Rewards 4.2 Managing Children's ASC / Other Needs and Impact on Self |

"We're all different"; Autism Impacts Parenting

This superordinate theme reflects participants descriptions of how being autistic is a difference, giving rise to unique strengths and difficulties when parenting.

Shared Diagnosis and Similarities. The majority of participants' children also had a diagnosis of ASC or were undergoing an assessment. Shared diagnoses helped participants feel closer and more connected to their children, such as a sharing a "*special bond*" (Oliva) or "*world*" (Leah), having "*natural relationship*" (Alice), "*common ground...to bond with and talk about*"

(Lucy) or being *“peas in a pod”* (Emily). Even in the case where there was not a shared ASC diagnosis, participants still noticed similarities between themselves and their children’s needs which were positive. Grace reflected that both she and her son were quieter and *“avoider[s]”*, which they were both *“quite happy”* with.

Participants reflected that shared diagnoses meant they had a more in depth or *“instinctive”* (Alice) understanding of their children’s needs compared with others; *“I’m the one who can get through to him”* (Leah). This helped participants meet their children’s needs:

“We’re the same...I can usually figure out what they want or need when they can’t always verbalise it and help them in ways that other family members can’t.” (Zoe).

Despite these positives, increased understanding compared to others meant participants were typically the main carers, had to explain or *“translate”* (Alice) difficulties to others, or *“mediate”* (Alice) conflicts. Participants reflected how their shared diagnosis led to challenges, such as balancing conflicting autistic needs and negative impact on self-care:

“...he drives me nuts with his sensory needs he likes being on top of me and all over me and climbing on me and I’m directly the opposite.” (Emily).

Many spoke of feeling guilty or blaming themselves for the experiences their children had, as they felt they *“passed on something possibly genetic.”* (Olivia). Often, this linked to having experienced similar struggles to their children and a wish to protect them:

“I feel bad that she feels so anxious a lot of the time [Crying] and I feel bad because I used to feel like that... I don’t want her to feel the way that I did.” (Sophie).

An Intrinsic Part of Self for Better or Worse. All participants reflected on how being autistic was a part of them and how their strengths and weaknesses in relation to parenting were, therefore, inherently related to being autistic. Consequently, many highlighted the impossible task of *“teas[ing] out the autisticky bits from the non-autisticky bits.”* (Leah). All participants reflected that being autistic resulted in both strengths and weaknesses for parenting. Some felt being autistic resulted in a *“normal”* (Leah), but more *“amplified”* (Alice) emotional experience of parenting which could be positive at times and overwhelming at others:

“We have lots and lots of empathy, but if it’s too much to deal with you have to just shut it off because it’s so overwhelming.” (Grace).

Several participants reflected on their analytical thinking, in-depth *“research”* (Ava, Alice), and planning of *“practical matters”* (Lucy) as positive and linking with their *“autism trait[s]”* (Ava). For example, participants linked such behaviour to a *“special interest”* (Alice), *“a desire for certainty”* (Zoe), or to a *“black and white thinking”* (Lucy) style¹⁰ resulting in a desire to be *“all in”* (Lucy) or to be *“the best parent I [they] could.”* (Alice). However, some acknowledged this planning could negatively impact other areas of life, such as social or work.

Many participants spoke of a need for routine which *“help[ed]”* (Emily) their children by giving *“consistency”* (Grace) and *“safety...security in our [the] relationship.”* (Lucy). For others, this routine was hard to achieve as there were *“demands being put on you all the time”* (Ava). Similarly, others struggled with

¹⁰ Synonym for rigid thinking style in ASC (American Psychiatric Association, 2013)

the constant nature of demands, which Leah termed “*demand overload*” and some linked to being autistic and “*demand avoidant*”¹¹ (Ava).

Participants also reflected on their social and communication differences, such as struggling to “*socialise with [other] parents*” (Zoe) due to difficulties with “*conversation that’s not like answering questions or specific*” (Olivia), feeling different, or sensory needs. Managing sensory sensitivities whilst parenting, especially in pregnancy, was another common difficulty:

“*I had to stop work at six weeks because my body was just in sensory overload.*” (Sophie).

Battle for the Right Support

This superordinate theme relates to participants’ shared experience that trying to make use of support was often a difficult process. Participants also reflected on what good support was, or could be like, and its benefits.

Misunderstood, Judged and Dismissed. All participants spoke of feeling misunderstood, judged or dismissed leading to difficulties in receiving support for themselves or their child. Participants reflected on how being misunderstood was typically linked to their autistic traits. Sometimes, judgement was positive, such as participants being seen as “*good at parenting*” (Olivia) or “*coping very well*” (Emily). Often this related to participant’s in-depth research, caring experience, or “*masking*” (Zoe). Unfortunately, this positive judgement led others to assume participants did not need support, as “*they [professionals] didn’t understand why we were asking for it*” (Alice). Sometimes support was

¹¹ Difficulty, and avoidance of demands, has been associated with autism, with some research suggesting Pathological Demand Avoidance is a subtype of autism where this difficulty is especially prevalent (National Collaborating Centre for Women’s and Children’s Health, 2011).

denied even when requests were very clear. For example, Lucy reflected that whilst in labour she felt “*vulnerable...the mask was up*”; meaning she did not appear as distressed as she was, nonetheless, she communicated her needs clearly, but to no avail:

“...*they [professionals] don’t believe you if you just say it, they want you to perform it.*” (Lucy).

Similarly, participants often reflected how their feelings or needs and outward expression of these were “*two very different things*” (Emily), leading to multiple misunderstandings. This mismatch led to difficulties with professionals as they assumed participants were “*aggressive*” (Grace) or experiencing “*anxiety*” (Olivia, Zoe) when they were “*upset*” (Grace) or had a need for “*certainty*” (Alice). This often resulted in dismissals or not being “*taken seriously*” (Olivia).

When professionals were not aware of participants diagnosis this sometimes led to a “*pressure*” (Lucy) to conform to “*unwritten social hierarchy*” (Alice). However, disclosing their diagnosis sometimes created further misinterpretations or negative judgements, such as professionals negatively judging participants ability to “*cope*” (Ava) or parent and viewing them as “*cold*” (Lucy). This then resulted in participants feeling patronised or exposed to stigma and intolerance of their difference:

“... *when he [GP] realised I was Autistic he wanted me to write down all of the times and dosages for (NAME-son)’s medicine (LAUGH), I was sat there going no it’s fine.*” (Emily).

Sadly, for many, this stigma led to an internalised belief of not being a “*good enough parent*” (Olivia) and to a fear of disclosure. The judgement participants were exposed to not only related to their own diagnosis of ASC, but

often inter-linked with their children's ASC or additional needs. Participants often felt "*parent-blamed*" (Sophie) for their child's difficulties or "*treated as a problem parent*" (Leah) when advocating for their child's needs. Many experienced significant dismissals of their concerns about their children's needs; for some this felt like being constantly "*pushed away*" (Sophie) by professionals and for others it was experienced as not being believed accused of "*making stuff up*" (Zoe).

Sometimes participant's own ASC diagnosis led to a reversal from this "*disregarded*" position in relation to understanding their child's support needs, to being taken "*seriously*" (Emily); linked to professionals viewing this as legitimate expertise. Nonetheless, these judgements, misunderstanding and dismissals resulted in "*undue stress*" (Lucy), "*anxiety*" (Sophie) and a persistent feeling that accessing the right support was a "*fight*" (Olivia, Ava, Leah), "*battle*" (Emily), "*mission*" (Grace), or a constant "*pushing*" (Alice); which some felt they were "*losing*" (Olivia) leading to "*withdraw[al]*" (Olivia) from support services.

Understanding ASC within the Family Unit. Many reflected good support systems required listening and an understanding of autism:

"People really need to listen to Autistic parents...were not thick, we see things from a different perspective." (Olivia).

Participants felt more respected and "*accepted as the experts*" (Alice) in their or children's needs by professionals that understood autism. Others recalled feeling "*validate[d]*" (Leah) or reminded "*it's just a different way and it's not necessarily the wrong way.*" (Grace). Understanding of autism also led to increased trust that support requests would be acted upon, rather than dismissed:

"I can just phone them [husband's parent] up and say 'I need your help, I'm really struggling.' And that's it, like, they'll help me." (Zoe).

Participants often wanted help with practical aspects of parenting which aided their self-care:

"I have an Au Pair so I just get more of the quality time with her... I'm not stressed all the time... that make a huge difference the fact that I get enough down time." (Ava).

Shared experiences (being autistic or parenting children with ASC or additional needs) often improved understanding in social support networks, leading participants to feel as though they had an "ally" (Grace) or supportive other:

"I have got some friends who have children who are very diversities themselves and therefore they get it far more than most." (Emily).

Participants also found support from their neurotypical partners who helped to accommodate for aspects of parenting that participants found difficult:

"(NAME-husband) was able to do the make-believe stuff that, I, I couldn't do." (Olivia).

Participants often commented on the importance of general healthcare professionals (such as "midwives", health visitors, GPs) and schools having training in "how autism presents" (Lucy) to improve support (for them or their child). Some felt this training needed a recognition that autistic adults may also be undiagnosed; especially if their children were autistic. Some felt strongly that services should be more explicit in considering if the parent is autistic:

"They [children's ASC service] just ask if you've got any diagnosis... And if the parent says no, that's just the end of it, but it could be that they have got

something there, but they've just not got a diagnosis, but they just don't ask that." (Zoe).

Similarly, several participants felt very strongly that, at minimum, if there were diagnoses, services needed to consider both child and parent's ASC:

"[Professionals need a] consciousness that a two-for, like an autistic parent with an autistic child is its own thing, that is different from either being a parent of an autistic child, or an autistic parent of a neuro-typical child. I think there's just zero recognition of that being a dynamic, and it's, for us, the defining dynamic that colours literally everything... and having to sort of separate those things out, is – is kind of absurd and unhelpful." (Leah).

Olivia highlighted the importance of this as she felt her own autism difficulties got in the way of meeting her children's autistic needs at times:

"I've got needs myself, I can't do it and my kids are entitled to this support but I'm going to have to say that they can't have it because I can't do the accounts." (Olivia)

Development and Acceptance

This superordinate theme reflects how participants described parenting as a process of adjustment, self-development and self-acceptance. This was linked to either participants receiving an ASC diagnosis or their general experience of parenting.

Diagnosis, Self-Care, & Self-Acceptance. All of the participants received a diagnosis of ASC (or self-identified in Sophie's case) after already becoming a parent. Prior to being diagnosed, some participants spoke of feeling "guilty" (Ava, Alice) for their difficulties and their impact on their children. Others recalled being diagnosed with other physical or mental health conditions, such as "*postnatal depression diagnosis and anxiety*" (Sophie), but feeling like these

did not fit and their experience was linked to autism. Receiving a diagnosis led to a “*re-process[ing]*” (Sophie) of participants’ experiences in a positive way. For many, this reduced feeling guilty, increased self-acceptance, and gave an explanation that felt it fitted with their identity:

“I’m a girl and I’m different and I’ve been misdiagnosed my entire life and it just made sense to me, my life just fell into place and I now love being Autistic, I love being allowed to be Autistic and not anxious.” (Olivia).

This increased understanding helped participants “*accept*” (Alice) being “*different*” as not “*wrong*” (Grace) and in turn gave participants permission, or the relevant “*understanding about [themselves]*” (Emily), to self-care, accept support, or access more appropriate support. There was a strong sense that such understanding and self-care resulted in them being “*better parent[s]*.” (Alice), although, many felt this increased understanding and practising self-care was an on-going process; “*I’m still trying to work it out.*” (Alice).

Growth and Adaptations. Many participants reflected on how parenting their children led to self-growth and acceptance:

“It’s taught me so much patience... it’s taught me to find joy in the little things, it’s taught me to live in the moment for me...to communicate on my terms, it’s taught me that there’s nothing wrong with how I communicate erm because these small people are understanding me and these small people have no life experience, no knowledge of communication, can understand exactly what I’m saying.” (Lucy).

Some reflected on how growth and “*managing [the] change*” (Alice) felt apart of parenting, such as observing growth and loss of some developmental stages as well as experiencing excitement for new ones. For many parents, changes and development within parenting were linked to making adaptations

or changes to support their children's ASC or additional needs. Many reflected that although change or flexibility was something they could struggle with (as linked to their autism) parenting helped them become more accepting of this:

"Autistic people aren't famous for coping well with change, but you know, it is what it is and you just have to kind of adjust as you go and just learn as you go." (Alice).

Sometimes making adaptations for their children needs felt a clash with participants' own autistic related needs. Nonetheless, although initially difficult, many still adapted:

"I'm not a very touchy-feely person, but...I had to get used to not minding...if my son's like climbing all over me...at first it got to me...but once I'd got used to it, you know, I just get on with it." (Zoe).

For some, adapting themselves to meet their children's needs was a positive experience resulting in them feeling *"proud of [themselves]"* (Olivia) or it being easier than expected:

"I was more laid back than I thought I would be, I was always a stickler for having rules in place more (LAUGH)..." (Emily).

The Ups and Downs of Parenting

This super-ordinate theme describes the positive experiences and challenges that participants felt linked to parenting.

Connection, Enjoyment and Rewards. All participants reflected on their *"connection"* (Zoe, Emily, Grace, Leah, Sophie), *"bond"* (Lucy) or *"love"* (Alice, Ava, Olivia) for their children. Many reflected on the intensity and strength of this connection describing it as *"overwhelming"* (Olivia), *"complete adoration"* (Leah) and *"strong"* (Zoe). Several commented their relationship was *"close"* (Lucy) or involved a sense of warmth and being *"always together"*

(Emily). Ava recalled fearing that her love was so immense for her first child it might not be as strong for her second but was pleasantly surprised:

“I was worried I wouldn’t love her as much, I just couldn’t see how anyone could be as good as (NAME-son) (LAUGH) and how could you have enough love for two babies, but ...it just wasn’t the case at all so you do get more love.” (Ava).

Participants reflected on the development of their connection. For some this felt like it *“just happened”* (Emily) and was *“absolute bonding straight away”* (Lucy); including before the birth or adoption of their child:

“You sort of fall in love with this child in your head before you’ve even met them.” (Alice).

“The first time I saw her it was like the most amazing feeling... and I looked in her eyes and it was like I’d know her forever... I can’t even ex, it was beautiful.” (Sophie).

For others the connection felt *“initially...awkward”* (Grace) or took time to develop. This was typically linked to other difficulties; for Grace this was around the adoption process being *“awful.”* For others, it was related to concern for other children, pregnancy issues, or post-natal depression. Participants also reflected on the changing nature of their connection, noticing it develop as their child developed. For most, this connection was similar in strength, but just *“different”* (Sophie, Alice, Lucy). For some, this connection was *“more”* (Zoe) or *“better”* (Grace) over time. For Olivia, her connection remained similar with her son, however, was not as strong as she hoped for with her daughter:

“(NAME-son2) comes to mummy for cuddles and loves which is really nice, (NAME-daughter) and I, I think she much prefers dad...and that upsets me.” (Olivia).

Participants noticed how children reciprocated their affection physically or verbally:

“Really often she will say “you’re the best mum in the world” and gives lots of kisses, she is very huggie and kissie.” (Ava).

They also expressed that their child’s love and reciprocated connection felt linked to children trusting their parent:

“Well, they both come to me when they’re upset about something, they both take comfort from me and if we go into a new situation they like to be close to me and they use me as a safe base.” (Alice).

Many parents reflected on how they “enjoyed” (Zoe) parenting or found it “fun” (Leah). For some this was linked to their strong connection and for others it was enjoyment of teaching their children and watching them grow. Many reflected on how rewarding the process of seeing their child develop was and how “proud” (Leah) they were:

“Seeing his progression and celebrating the wins and the small things that other parents would take for granted... for us is a huge celebration.” (Emily).

Managing Children’s ASC / Other Needs and Impact to Self. For many, managing their children’s ASC or other additional needs was the “*hardest thing*” (Ava) when parenting. For some, this was related to their child being “*different*” (Sophie) and feeling they did not fit in “*the normal mum’s club*” (Sophie). For others, it was related to the “*extra difficulties that other parents don’t have.*” (Zoe). Many described struggling with the impact on themselves from parenting, such as lack of sleep and exhaustion, especially with new-born babies and the demands (emotional and physical) of “*breastfeeding*” (Olivia):

“I didn’t have two thoughts to rub together, and that was almost panic inducing. Like, it was like I felt like I was just being taken to pieces. And there was nothing left of me.” (Leah).

Similar to Leah above, several of the participants spoke of the emotional impact of parenting. For some, this began when trying to start a family:

“The last six years have been hell doing IVF the whole time and I was just exhausted.” (Ava).

For others this started, or continued, when they had new-born babies or difficulties arose in providing care:

“He [son] started disclosing some significant abuse [from when he was adopted] which...I just didn’t have the capacity to deal with...my emotions around it.” (Alice).

Often the emotional impact was linked to feeling not good enough, a “failure” (Zoe, Olivia), or an “imposter” (Grace) as a parent. This led to high anxiety, guilt, or fear that participants were “doing everything wrong” (Sophie). Often this emotional impact was linked to children’s autism or additional needs. For some, these feelings felt “classic” (Leah) parenting experiences that were not “anything special to Autistic people” (Lucy). For others it felt linked to their autism, as well as their child’s.

Discussion

The aim of this study was to explore the lived experiences of autistic parents. Four superordinate themes were established; ‘*“We’re all different”: Autism Impacts Parenting*’, ‘*Battle for the Right Support*’, ‘*Development and Acceptance*’, and ‘*The Ups and Downs of Parenting*’.

The first superordinate theme ‘*“We’re all different”: Autism Impacts Parenting*’ reflects a narrative that autism impacts parenting, resulting in unique

strengths and challenges. This is in agreement with Robertson's (2010) work in suggesting that rather than a narrative of deficit, a narrative of neurodiversity is more appropriate as autism gives rise to unique strengths and difficulties.

Autistic adults have been noted to have strengths in their love of learning (Kirchner et al., 2016), linked to engagement with special interests (Teti et al., 2016). These strengths were noted in the current study, in that participants often described parenting and caring for others as a special interest which lead to them thoroughly research around this. For some parents, this researching and their parenting style generally, was also linked to another ASC trait of rigid thinking (APA, 2013); participants described needing to be 'all in' and fully committed to being as good a parent as possible. These traits resulted in family and friends commenting on participants' good parenting or seeking advice from them.

In terms of unique difficulties, the current study indicated that changes and sensory issues associated with parenting were of particular difficulty; consistent with the diagnostic criteria for autism (American Psychiatric Association, 2013). In terms of sensory difficulties, this appeared most prevalent and hardest during pregnancy. It is of note that, despite these difficulties, participants adapted to change or adapted themselves in order to meet the needs of their children. This is consistent with Pohl et al. (2020), who found autistic mothers had increased parental difficulties compared to non-autistic mothers but nonetheless overcame these in order to put their child's needs first. Another consistently reported difficulty in the current study was that of intensified feelings and empathy for their children, which was overwhelming at times. This is in line with research that suggests that although autistic individuals may have some difficulty with cognitive empathy (perspective

taking), they appear to have heightened emotional empathy (directly feeling the emotions another is feeling) which can be overwhelming (Smith, 2009).

Within the first superordinate theme it was also noted that most participants' children also had a diagnosis of autism, which was described as giving an instinctive understanding and ability to meet children's needs. Some participants described that, in turn, this resulted in them being the main carer, having a deeper bond with their child than others and their child seeking them out for support. Attachment theory research (Bowlby, 1958; Fahlberg, 1991) provides a possible explanation for this as it suggests that through attunement and meeting of children's needs secure attachment, trust, and bonds are formed.

There was a lack of emerging themes around co-parenting experiences which may be as participants typically reported being the primary carers and that partners (all male) tended to have a supportive role, such as providing aspects of care that the participant struggled with due to their ASC or in supporting the participant with the impact of parenting. Parents in the study also found support from others with similar experiences, in particular other autistic adults. This links with research that suggests relationships between autistic adults involve a sense of acceptance and belonging (Sinclair, 2010).

The second superordinate theme, '*Battle for the Right Support*' reflects difficulties participants experience in accessing appropriate support for themselves and their child, such as being subjected to judgement and stigma, consistent with current literature that suggests such experiences are common (Holton et al., 2014) and that judgements are often made quickly (Sasson et al., 2017). This is likely linked to a lack of understanding and negative stereotyping around autism (Harnum et al., 2007; Wood & Freeth, 2016). Additionally, within

the study such misunderstandings, dismissals and negative judgement were often from neurotypical individuals. This is consistent with previous research (Holton et al., 2014) and supports Milton's (2012) 'double empathy problem' theory (DEP); that neurotypicals and autistic individuals equally struggle to empathise and understand one another, rather than autistic individuals having an empathy deficit. The DEP and negative stereotypes may account for why many individuals and professionals in the study struggled to understand or meet the needs of participants. Similarly, a lack of awareness of masking (Hull et al., 2017), assumption of good parenting (linked to autistic strengths of preparation), and differential display of emotional affect, were noted in the study and may contribute to professionals doubting the stated word of individuals.

Negative judgement, misunderstanding and dismissals were not only related to participants ASC diagnosis but also linked to their child's ASC. This is consistent with research that shows parents struggle to access support for their child with ASC and it often feels like a 'battle' (Vassallo & Griffin, 2016). Although it is of note that Pohl et al. (2020) found autistic parents experienced increased misunderstanding and difficulties with professionals compared to non-autistic parents, when both groups were parenting an autistic child. It appears, therefore, that this may be a compounded difficulty for autistic parents with an autistic child. Linked to this, this superordinate theme highlighted how services lacked consideration for both child and parent's autism diagnosis at the same time. This is reflected in how current services are set up in the UK as either adult or child services.

The third and fourth superordinate themes '*Development and Acceptance*', and '*The Ups and Downs of Parenting*' highlight a narrative of autistic parenting being similar to general parenting experiences, involving joy

and connection but increased stress (Louie et al., 2017). This finding, and the existence of autistic parents themselves, contradicts prevalent stereotypes of autistic individuals being ‘emotionless’, not wanting, or struggling to form, relationships, including sexual relationships (Wood & Freeth, 2016; Urbano et al., 2013). This is akin to the finding from Kaspar and Kroese (2017), who found adults with learning disabilities felt their attachment experience was the “*same as anybody else*” (p.112), but stigma they faced from others, including services, created difficulty.

The third superordinate theme particularly highlighted the importance of receiving an ASC diagnosis, as this supported self-understanding and self-care, consistent with previous findings (Hearst, 2015; Leedham et al., 2020), which in turn was described as improving parenting. The fourth superordinate theme particularly highlighted that many parenting difficulties were related to their child’s ASC or additional needs. This reflects prior research which suggests having an autistic child or child with other difficulties can result in increased difficulties and parental stress (Anderson et al., 2020; Pelchat et al., 1999).

Methodological Critique and Directions for Future Research

Despite recruiting for both mothers and fathers, all participants were mothers and typically the main carer. Many participants were recently diagnosed with ASC, had children with ASC or additional needs, and typically received their own ASC diagnosis following a diagnosis in their child.

Additionally, many participants had extensive childcare experience or parenting was a special interest which may have been a motivator for their participation in the study. These factors may have influenced participants perspective’s and limit the transferability of the results. Future research may wish to investigate

experiences of fathers, neurotypical partners of autistic parents, as well as of various dyads of parents and children in relation to ASC diagnoses.

The study had strengths in its use of reflexivity and auditing in order to reduce bias and ensure transparency. However, it is of note that the main researcher is not autistic and, as with all qualitative research, it is difficult to remove all bias. Findings should, therefore, be interpreted in light of this.

The study also has strengths in its involvement of service users for the materials used, as well as having flexible methods for data collection, for example, Skype; this may have aided participants to feel comfortable during interviews.

The study indicated that autistic birth mothers may experience difficulties with sensory sensitivities during pregnancy and further research would be beneficial in this area. It also highlighted a high level of misunderstanding and judgement regarding autism which may be in part due to the impact of the DEP; it would be important to further understand how the DEP may impact healthcare professionals working across general child or parental settings. Additionally, the current study highlighted that autistic individuals have many unique strengths, and that there is a need for further research into strengths of autistic individuals.

Clinical Implications

The study highlights how separation of child and adult autism services can complicate implementing support in family units where both parent and child have ASC. Consideration to the family unit as a whole and the dual impact of parent and child having ASC is, therefore, needed within services. For example, children's services could consider recommendations in light of parents' ASC needs and own views of what feels manageable and realistic. Additionally,

services could reflect on ways to support both autistic child and autistic parent simultaneously. Participants in the review also advocated for children's services to consider more fully the possibility that parents with children with ASC may have a diagnosis themselves; it may, therefore, be useful for such services to provide information to families about this possibility and education on how autism presents in adulthood.

The current study highlights the need for increased education, training and understanding of ASC within general healthcare services. In particular, education on how autism presents in adulthood, masking, mismatching of emotional experience and facial expression, sensory needs (especially in pregnancy) and the DEP is needed. The study supports the importance of hearing from autistic individuals themselves and therefore advocates for co-production when delivering such training.

Additionally, a narrative of difference, rather than deficit should be adopted, as well as countering stereotypes and over-simplifications, such as autistic individuals lacking empathy, is important. Similarly, highlighting how autistic individuals have unique strengths and are able to create and maintain relationships, including having families and being good parents, would be beneficial. Implementing these recommendations could reduce misunderstanding and stigma, as well as reduce internalised guilt in autistic parents.

Additionally, considering the prevalence of mental health difficulties in autistic adults, and how parenting can increase stress, improved access for ASC tailored psychological support may be required. It would also be helpful for services to signpost to, or support development of, autistic parent support groups.

Conclusions

The study highlights that autistic parents experience similar ups and downs of parenting to non-autistic parents (such as enjoyment, strong connection versus increased stress). Autistic parents also experience unique strengths and challenges in relation to parenting; such as high levels of preparation versus sensory difficulties. The hardest and most common difficulty related to misunderstandings, judgement and dismissals from others, especially professionals. Largely, the participants' children in the current study had ASC or additional needs which led to increased judgements from others. However, this shared diagnosis also appeared to increase understanding and strengthen the parent-child bond.

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Appendix A: Ethical Approval and Considerations



Downloaded: 04/06/2019

Approved: 03/06/2019

Amber Dugdale
Registration number: 170149341
Psychology
Programme: Doctorate of Clinical Psychology

Dear Amber

PROJECT TITLE: Lived Experiences of Autistic Parents: An Interpretative Phenomenological Analysis

APPLICATION: Reference Number 024239

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 03/06/2019 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 024239 (dated 31/05/2019).
- Participant information sheet 1063007 version 1 (31/05/2019).
- Participant information sheet 1063006 version 1 (31/05/2019).
- Participant information sheet 1060049 version 2 (31/05/2019).
- Participant consent form 1055035 version 1 (08/01/2019).

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Yours sincerely

Jilly Gibson-Miller
Ethics Administrator
Psychology

Ethical Considerations

Informed Consent. Participants were provided with information sheets prior to commencing the study explained details of the study and the right to withdraw. During the study, participants were given the opportunity to ask questions, review the consent form and be reminded of their right to withdraw from the study at any time.

Confidentiality. There was potential that disclosures of risk to self, others or children, could occur in the interviews. The role of the researcher, and the limits to confidentiality, therefore, were clarified (Forbat & Henderson, 2003) and checked they were understood prior to commencing interviews. Following the interview participants were offered the opportunity to discuss anything they found difficult about the interview and reminded of areas of support they could access if needed (for example, their GP). Any concerns regarding risk were discussed at the end of the interview schedule and then discussed with a research supervisor following the interview.

Location. Individuals with autism can find attending a new environment difficult, and home visits or online interviews were preferable to some participants. Skype interviews have been utilised successfully in autism research by MacLeod, Allan, Lewis, and Robertson (2018). The NHS home visit guidance (see below) was followed when home interviews were carried out. Prior to the interview at the University of Sheffield additional information (for example, pictures, maps and descriptions) was given to each of the participants to help reduce the anxiety of attending a new location.

Home Visit Guidelines

1. If possible, obtain information about the participants who are being visited at home. For example, does the participant have a known history of aggression?
2. Obtain information about the location of the home visit. For example, does the area have a reputation for being unsafe, isolated or poorly lit?
3. Consider the nature of the relationship between the participant and researcher, and the purpose of the home visit. For example, is the person likely to be 'suspicious' of professionals?
4. Trainee to set up google calendar, once appointments are arranged. This google calendar will be shared with the research team/supervisors.
5. Ensure the trainee details where and when they are making a home visit and their anticipated return.
6. On arrival the trainee will text a "buddy" within their research team; they will also text on departure.
7. If the "buddy" has not heard from the trainee after two hours of the appointment end time; they will ring the trainee.
8. When home visits are made at the end of the day, explore what possibilities exist to allow the trainee to inform a member of the supervisory team that they have completed the visit safely.
9. Emphasise the importance to the trainee of maintaining therapeutic boundaries, for example, by not disclosing personal information such as home address or telephone number.

* This is adapted from: Clinical Psychology Services, Central Nottinghamshire Healthcare NHS Trust guidelines.

Appendix B: Advert for IPA Study

Do you have a diagnosis of autism? Are you a parent of a child between 5-10 years of age?

I am looking for participants for a research study aimed at better understanding the experiences of autistic parents.

This will involve taking part in an hour-long interview about your experience of parenting and how being autistic may impact this experience. We hope that the research will be helpful for tailoring services to autistic parents and have implications for the services of their children too.

I am a Trainee Clinical Psychologist and this project will form part of my thesis. You will be eligible to take part if you:

- Have a formal diagnosis on the autism spectrum (e.g. autism; Asperger Syndrome; High-functioning autism; autism spectrum condition/disorder)
 - Are a parent
 - Do not also have a diagnosis of a learning disability
 - Are fluent in English
 - Are over 18 years of age
- Currently a parent to child between 5-15 years of age

Please do get in touch if you have any questions and/or are interested in participating and further information will be provided.

Amber Dugdale: asdugdale1@sheffield.ac.uk.

Appendix C: Participant Information Sheet



**Amber-Sophie Dugdale
Trainee Clinical Psychologist
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield S1 2LT
UK**

**Email:
asdugdale1@sheffield.ac.uk**

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research project. Before you decide, it is important to understand why the research is being done and what it will involve. Please read the following information carefully and ask me any questions you have.

Why have I been invited?

You have been invited to take part in this research project because you are an adult who has a diagnosis on the autism spectrum who also is a parent.

Do I have to take part?

No, it is up to you whether you would like to take part. Participation in this study is voluntary. If you decide to take part, you can keep this information sheet and will be asked to sign a consent form. You can withdraw at any time without giving a reason.

What will happen if I take part?

You will be contacted via telephone or email (please indicate which is your preferred method) by the lead researcher within 3 weeks. You will be asked to

take part in an hour-long interview where you will be asked some questions about your experience of parenting and how your autism may impact this experience.

The interview will take place at the University of Sheffield, or the researcher may come to your home to carry the interview out. You are welcome to bring with you a supportive individual if this would help, however they are unable to participate during the interview. If neither of these options are suitable, an alternative arrangement of a Skype interview could be arranged.

This interview will be recorded and then transcribed using an approved University of Sheffield transcriber. Following this it will be analysed using Interpretative Phenomenological Analysis.

What are the benefits of taking part?

You have the opportunity to share your experience of parenting. A written report of the findings will be published and we hope that this may be helpful for tailoring services to autistic parents and may have implications for the services of their children too.

What if there is a problem?

If you feel that there is a problem at any time, you can let the researcher know. This may be a topic that is difficult to talk about or could feel distressing. If you experience any distress whilst sharing your experience, the researcher will be able to discuss this with you and discuss what further support might be of help (e.g. contacting your GP).

Will all the information be kept confidential?

All the information we collect about you will be kept strictly confidential. You will not be identifiable in any reports or publications.

The only exception to this would be if during the interview the researcher became concerned about a risk of harm to yourself (e.g. suicidal risk), or someone (e.g. a child or another adult) you talk about (e.g. risk of neglect or physical harm). In such a situation the researcher would discuss the need to breach confidentiality with you; the aim of this would always be in order to support yourself and those you mention and ensure safety (for example, it may involve letting relevant services know about the situation in order to help provide those involved with support).

Will I receive any reimbursement of expenses for taking part in this research?

There will be reimbursement of relevant travel expenses incurred by participating in this research (subject to providing receipts of travel). You will be asked to attend the University of Sheffield or the researcher may come to your home to carry out the interview.

What will happen to the results of the study?

The results will be submitted as part of the researcher's doctoral thesis in May 2020, then prepared for publication in 2020. You can let the researcher know at the start of the study if you would like a copy of this and this can be sent to you. The University of Sheffield is organising and funding this research. This project has been ethically approved via the University of Sheffield Clinical Psychology department, using the University of Sheffield's Ethics Review Procedure.

What if I wish to complain about the way the study has been carried out?

In the first instance you can contact the lead researcher, Amber Dugdale on asdugdal1@sheffield.ac.uk. Alternatively, you can contact the other researchers involved in the project; Megan Freeth, Lecturer and Researcher on

m.freeth@sheffield.ac.uk or Andrew Thompson Director of Research Training at the University of Sheffield on a.r.thompson@sheffield.ac.uk.

If you feel that your complaint has not been handled to your satisfaction following this, you can contact Dr Glenn Waller, Head of Department on G.Waller@sheffield.ac.uk or Dr Thomas Webb, Chair of the University Ethics Committee on T.Webb@sheffield.ac.uk

Contact Information

This research is being conducted by **Amber Dugdale**, Trainee Clinical Psychologist. This research will be used to write a thesis which fulfils part of their doctoral training. If you have any questions about the research, you can leave a telephone message with the Research Support Officer on: 0114 222 6650 and he will ask **Amber Dugdale** to contact you.

Additional Information about your data

New data protection legislation came into effect across the EU, including the UK on 25 May 2018; this means that we need to provide you with some further information relating to how your personal information will be used and managed within this research project.

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'.

As we will be collecting some data that is defined in the legislation as more sensitive (e.g. information about your health, we also need to let you know that we are applying an additional condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

Appendix D: Participant Consent Form



Amber Dugdale
Trainee Clinical Psychologist
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield S1 2LT
UK

Email:
asdugdale1@sheffield.ac.uk

Title of Research Project: Lived Experiences of Autistic Parents:

An Interpretative Phenomenological Analysis

Name of Researcher: Amber Dugdale

Participant Identification Number for this project:

Please tick the appropriate boxes

Yes

No

1. I have read and understood the project information sheet or the project has been fully explained to me. ☐ Yes ☐ No

N.B. If you answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.

2. I have been given the opportunity to ask questions about the project. ☐ Yes ☐ No

- | | | | |
|----|---|--------------------------|--------------------------|
| 3 | I agree to take part in the project. I understand that taking part in the project will include participating in an interview that will be audio recorded. | <input type="checkbox"/> | <input type="checkbox"/> |
| 4 | I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. | <input type="checkbox"/> | <input type="checkbox"/> |
| 6 | I understand that my responses will be kept confidential meaning that I will not be identified or identifiable in the report or reports that result from the research. | <input type="checkbox"/> | <input type="checkbox"/> |
| 7 | I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this. | <input type="checkbox"/> | <input type="checkbox"/> |
| 8 | I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form. | <input type="checkbox"/> | <input type="checkbox"/> |
| 9 | I agree for the data collected from me to be stored anonymously and potentially used in future research. | <input type="checkbox"/> | <input type="checkbox"/> |
| 10 | I agree to take part in the above research project. | <input type="checkbox"/> | <input type="checkbox"/> |
| 12 | I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield. | <input type="checkbox"/> | <input type="checkbox"/> |

Name of Participant Date Signature

Lead Researcher Date Signature

To be signed and dated in presence of the participant

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form and the information sheet. A copy of the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Appendix E: Reflexive Diary Excerpt

19th September 2019

First and Second Interviews (Skype and then Home Visit) (P3; P1). found my first interview really interesting. There were already topics coming up and things that I had never considered. For example, the participant spoke about being aware of their pregnancy early on due to sensory sensitivities during pregnancy. I was also struck by the level of distress in today's interview. The participant's child had struggled a lot due to their own autism and the participant had a lot of concern for the child; partly due to understanding from their own experiences how difficult things could be. I felt mindful that in future I will need to be empathetic at times like that in interviews, but also allow space to explore these things as I noticed I felt cautious today about the participant being distressed.

After the home visit interview, I noticed myself already noticing or interpreting comments as possibly about autism experiences such as noticing literal responses, memory differences, rule based or rigid thinking. I was also aware of my own biases; although I felt I had less assumptions about what an individual with autism adult life might be I noticed I had some assumptions today I wasn't as aware of. The participant previously had a very social, caring professional role; they also spoke a lot about emotions and the importance of these. Although I believed those with autism do experience empathy, I felt that they may have difficulties expressing this. This participant today actually had an interest from a young age in people and, therefore, learnt lots of social interaction skills. I felt warm to the participant in the interview. I will have to be mindful in the future to be aware to not make assumptions about what roles people may have or about their socialising skills. This participant spoke about

masking a lot and I will also need to be mindful that even those who display lot of empathy well, may still struggle and feel drained by the interview and find it difficult.

Appendix F: Example Transcript with Initial Coding and Emerging Themes

| | | | |
|--|---|---|---|
| | I | How do you think that they think of you as their parent? | |
| | P | Erm it really depends what mood they are in. | Opinion of parent dependent on children's moods. |
| | I | (LAUGH) | |
| <p>Child giving lots of love & physical affection</p> <p>Children expressing strong mixed feelings to parents; dependent on mood</p> | P | <p>Like there's been days when (NAME-daughter), what, what was it that caused the last argument, there was one argument where she was running up the stairs going "get the adoption papers (SHOUTING)" (LAUGH) "I want a new mum" (LAUGH) but then really often she will say "you're the best mum in the world" and gives lots of kisses, she is very huggie and kissie which is the opposite of her brother, so erm I think that they love us a lot and show it, (NAME-son) does show it too but not by hugs or kisses, he kinds of, he asks you to come and scratch him back or scratch</p> | <p>Questioning language.</p> <p>Arguments leading to daughter expressing dislike for parent – wanting to change families.</p> <p>Emotive, rejecting language.</p> <p>Caring, complementary language.</p> <p>Physical affection linked to assumption views parent positively.</p> <p>Participant feels children love parents and show it.</p> <p>Children show their care differently – son still physical connection but meeting sensory needs?</p> |

| | | | |
|--|---|---|---|
| | | his head erm and he likes to lie on me, put all his weight on me which I like too, that's a, I guess that's a sensory thing. | |
| | I | Yeah | |
| Affection linked to play / seeking out parent | P | And so he will, he will show the affection by coming and diving on you when you're in bed and playing, erm but he would never give you a hug or a kiss. Erm I've forgotten what the question was again? | Tentative language. Affection linked to child seeking parent out and play. |
| | I | Just how you think they think of you as their parent? | |
| Love & trust reciprocal Daughter changeable view based on getting things/mood | P | Yeah so I think they both love us a lot and erm I think they trust us but then (NAME-daughter) will, when, she is much more, I don't know if short tempered isn't the right word because she is not, (NAME-son) would be more short tempered but she is quite strong willed and if she can't have what she wants then she will start shouting; "you're the worst mum ever" even though five | Participant feels love and trust with children. Daughter can be changeable in her moods and expression of how she sees her parents based on when she is given things she requests. Tentative, questioning language. |

| | | | |
|---|---|---|---|
| | | minutes ago she was saying “you’re the best mum ever” and saying she wants to get adopted (LAUGH). | |
| | I | And do you think being Autistic has affected your relationship as she has got older? | |
| All having diagnosis helps relationships | P | Erm I think it’s good for us because she has got, she talks, they both talk about Autism quite happily and freely, erm and they get my perspective of Autism which isn’t as negative as the medical module perspective, erm so I think that’s good, it’s been good for them yeah. | Positive language. Tentative language. Feels helpful for children and participant to share a diagnosis as models a view that feels less prescriptive. What about medical model feels negative? |
| | I | And what are the ups and downs of being a parent to (NAME-daughter)? | |
| Time to self helps Together enjoyable Support helps manage practical demands | P | Erm the ups that it’s really nice to have her around, do stuff with her, she is really hilarious so it’s just nice having her around and she is very loving. The downs would be tiring but now they’re older it’s not as tiring, that was the down when she was younger | Positive, emotive, together based language – enjoying time together, fun. When younger physical impact – tired hard. Having practical support and child being occupied in day means time do have more valuable. |

| | | | |
|---|---|---|--|
| | | <p>but erm she goes to school three days a week, I have an Au Pair so I just get more of the quality time with her and not, I don't, I'm not stressed all the time like some mum's, and that, I think that make a <i>huge</i> difference the fact that I get enough down time which I didn't when they were babies.</p> | <p>Self-comparing language in positive sense – feels lacking stress.</p> <p>Time to self that gets helps manage stress of parenting.</p> |
| | I | <p>Yeah. Are there any stressors that you feel kind of have been linked to being a parent?</p> | |
| <p>Stress to balance own needs with children's needs</p> <p>Anxiety/stress linked to children's needs/own stress</p> <p>Masking of child; limited support</p> <p>Unsure how much to fight for support</p> | P | <p>Any stress? Erm all the stuff to do with their schooling issues, having to Home Ed when I didn't want to, erm worrying about the future mainly for (NAME-son) to start with but now probably more for (NAME-daughter) because she masks so much, on paper she has barely got any issues but I know that she has anxiety and worry and like being scared and social issues but other people don't see that, there's no way we can get any EHDP successfully I don't think so she is going to have to go to secondary school</p> | <p>Stressors linked to meeting children's needs when against own needs and anxiety for future.</p> <p>Anxiety and stress has changed or been more prominent for different children over time.</p> <p>Concerning language for daughter – acknowledgment how others see it and feels lack awareness of masking. Daughter struggle with anxiety and socialising.</p> <p>Masking hinders getting outside help – leaving without support at school.</p> <p>Hesitant, conflicted language.</p> |

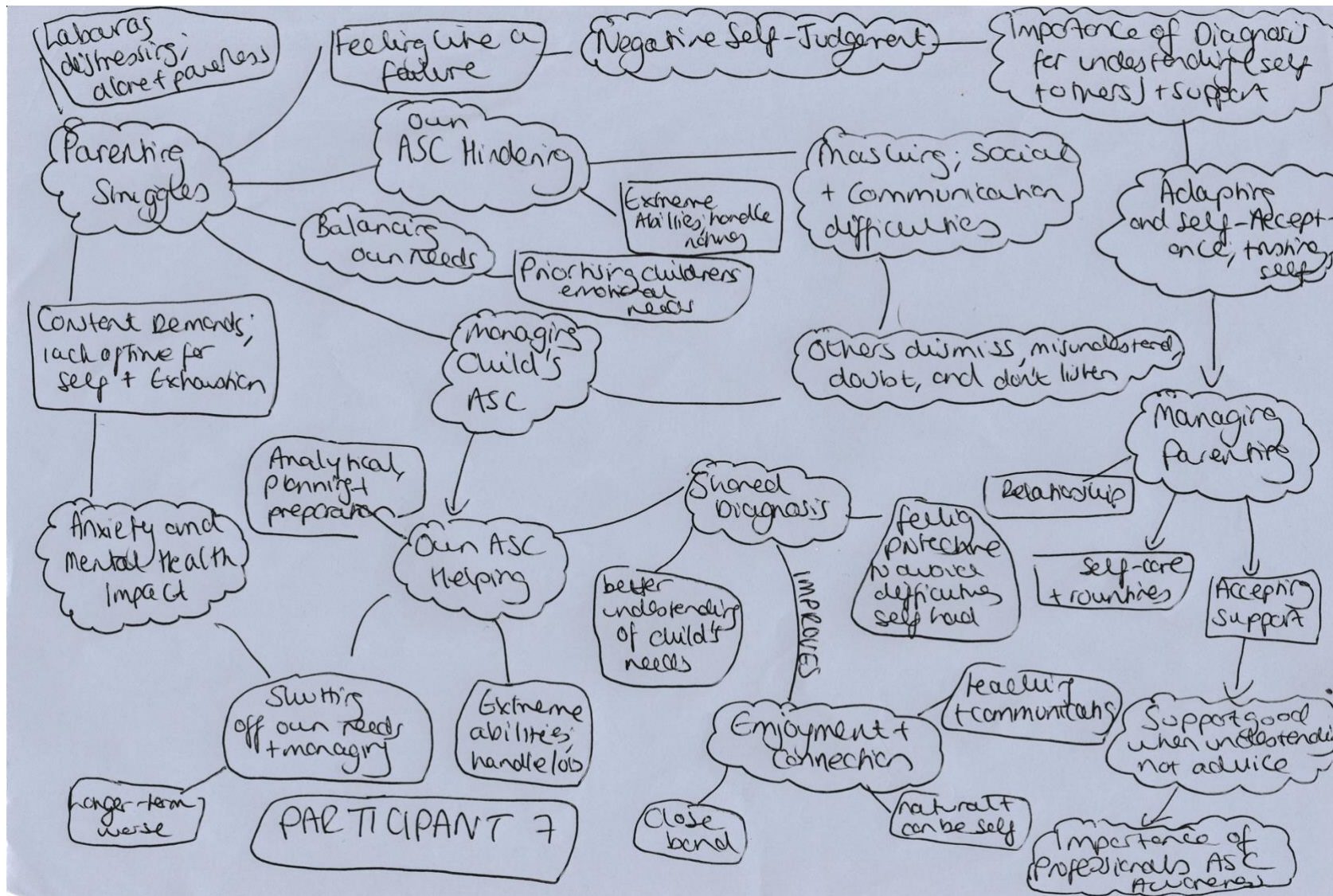
| | | | |
|---|---|--|--|
| | | <p>without one maybe. I dunno I might try and get one nearer the time but we could probably might not be successful because there is nothing on paper, school thinks she is doing fine, erm so I'd say if anything I'd be more, more worried about her now because she is in a tiny school with sixteen people and then she will have to go to secondary school.</p> | Anxious language for the future. |
| | I | It's hard | |
| <p>Increased awareness and confidence (child's needs and management)</p> <p>Not doing what society expects but doing what is best for child</p> | P | <p>But we have more knowledge ourselves and we would just take, if it went wrong we would take her out, Home Ed and then try and get and EHDP and get better support rather than how your sup, how people are expected to do it which is keep them going, keep them going until, it will take a year to get an EHP and then they're like really, really, really stressed. We would do what we did with (NAME-son) which is take her out and then keep her safe at home while we sort her out with the EHP.</p> | <p>Feel more aware of needs and prepared to manage difficulties. Planning language.</p> <p>Feels pressure to force child to stay in school until paperwork completed meanwhile child is distressed. Participant feels will not do the way it's expected from having learnt previously what is best for children.</p> |

| | | | |
|---|---|--|--|
| | I | Yeah and how was kind of like the ups and downs were they kind of, was anything about them different from what you expected? | |
| Child's autism wasn't expected Family feels different Not able to go out easily Split responsibilities to better meet children's different needs | P | <p>Probably the fact that they are autistic, so I didn't know anything about it at all and our family is completely different to the average family, we can't just go out for the, like I had all these ideas of going for day trips and things like you see other people doing but we can't do that stuff because of (NAME-son) he doesn't hardly leave the house. We occasionally go out with (NAME-daughter) and leave him with a baby sitter or quite often (NAME-husband) and (NAME-daughter) will go out and I will stay in with (NAME-son) because I prefer staying in more than (NAME-husband) does, (NAME-husband) goes crazy if he is in the house for too long.</p> | <p>Unexpected for children to be diagnosed. Lacked knowledge about autism. Expected to have family day trips, self-compared and assumed would be average and similar – but was not the case due to children's autism needs. Balance different needs of children by splitting responsibilities.</p> |
| | I | Yeah | |

| | | | |
|--|-----------------|---|--|
| <p>Family life not the norm</p> <p>Lack of understanding from others re autism</p> <p>Accepting and adapting to own family needs</p> <p>Adapting to have normal things</p> | <p>P</p> | <p>Erm so probably that's the other things, I've my life doesn't look anything like other people's. We used to go on holidays and visit friends, we can't do that, erm so friends who don't know about Autism they don't really get it so like they planned, some of our friends planned for us all to meet up in a park, I just don't think they realised there is no way we could take (NAME-son) with two other families in a park because the other people live far away, so take them in a car for a day in the park having a picnic with strangers cos they're not close to us geographically, they just don't really know what's been, been going on over the last few years, erm so we can't do stuff that other people do but I'm fine with that now, it, it took a bit of getting used to but we don't, we just say no to stuff and do our own thing and if, we could go on holidays but we have to make sure we have got Wi-Fi in the room for (NAME-son) and we have to check out what the food is cos he</p> | <p>Life feels different to the norm. Stopped holidays/seeing friends. Definitive, unable language. Lack of understanding from others who are unfamiliar with autism – as not present</p> <p>Understanding that some would see travelling in car wouldn't be issue.</p> <p>Accepting of differences had to adjust to – struggled at this initially.</p> <p>Adjusted by doing own thing. Still able to go away – just need adaptations.</p> <p>Amused language.</p> <p>Anticipation for how sons needs may adapt and may be able to access “normal family holidays”</p> |
|--|-----------------|---|--|

| | | | |
|--|---|---|---|
| | | <p>has a limited menu. Have a swimming pool in the pool in the hotel because he often doesn't leave the hotel so then quite often it's just a holiday in the hotel LAUGH), we don't really go anywhere, erm but as he gets older we might be able to leave him sometimes in the hotel but he is only ten at the moment so we can't do that yet but so we might find a, we went to Cape Verdi once and then you could just stay on the hotel resort and there are like quite a lot of pools and things and buffet meals so that was perfect cos we could be by the pool and he was just a few metres away in the room.</p> | <p>Have managed to have holidays – example of this.</p> |
| | I | Sounds nice (LAUGH). | |
| | P | Yeah. | |
| | I | And do you think yourself being Autistic has effected the ups and downs? | |

Appendix G: Conceptual Map



Appendix H: Participant Contributions to Subthemes

| Superordinate and Subthemes | Participants | | | | | | | | |
|--|--------------|-----|--------|------|-------|-------|-----|-------|------|
| | Olivia | Ava | Sophia | Lucy | Emily | Grace | Zoe | Alice | Leah |
| “We’re all different”; Autism Helps and Hinders Parenting | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Shared Diagnosis and Similarities | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| ASC Traits | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| The Ups and Downs of Parenting | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Connection, Enjoyment and Rewards | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Managing Children’s ASC / Other Needs and Impact to Self | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Battle for the Right Support | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Others as Misunderstanding, Judging and Dismissive. | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Understanding ASC, the Family Unit & Practical Help | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Adjusting & Acceptance | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Diagnosis, Self-Care, & Self-Acceptance | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Parenting as Growth and Adaptations | ✓ | ✓ | | ✓ | ✓ | ✓ | ✓ | ✓ | |

Appendix I: Audit Checklist

1. Is there evidence that raw data was collected and is appropriate for the research aims? (As evidenced by anonymised transcripts/interview schedule/listening to recordings)

Yes/Partially/No

2. Has relevant demographic and background information been collected to contextualise the sample (e.g. gender, age, interview location/time)?

Yes/Partially/No

3. Are field notes made by the researcher as part of the reflexivity process?

Yes/Partially/No

4. Has the data been sufficiently coded?

Yes/Partially/No

5. Has the data been systematically coded? (i.e. line by line in the right-hand margin focusing on linguistics, concepts and descriptive comments, emerging themes in left hand margin)

Yes/Partially/No

6. Has the researcher engaged in a process of refining and redefining the themes and subthemes and are these processes justified? (This may be evidenced by looking at different versions of the Word documents and notes, and changes to coding/themes).

Yes/Partially/No

7. Looking at randomly selected excerpts from the data against the corresponding coding and themes recorded in Word– are these consistent?

Yes/Partially/No

8. Are quotes sufficient to provide evidence of these themes and subthemes?

Yes/Partially/No

9. Does the results/write-up sufficiently address the aims of the study?

Yes/Partially/No

Signature of researcher

Signature of auditor

Appendix J: Selection of Illustrative Participant Quotes Per Theme

| Superordinate Themes | Subthemes | Additional Quotes |
|---|--------------------------------------|---|
| “We’re all different”; Autism Helps and Hinders Parenting | Shared Diagnosis and Similarities | <i>“I think we have had different things that are good or bad, erm it certainly helped me be accepting of them being Autistic.” (Ava).</i> |
| | | <i>“Her always wanting your attention...that’s challenging, because, I, I need time on my own.” (Ava).</i> |
| | | <i>“I think because (NAME-son) and I are so similar in so many of our structural requirements of the timeline and everything else it works very well because were both running off routines.” (Emily).</i> |
| | | <i>“I wasn’t masking with that at all, I wasn’t trying to hide who I was.” (Lucy).</i> |
| | | <i>“I can’t separate the Autism from any of it.” (Lucy).</i> |
| | | <i>“Because they’re autistic as well I have a good understanding of how their minds work and what they’re thinking or feeling that other people just don’t have.” (Zoe).</i> |
| | | <i>“Now that we’ve both been diagnosed, I can say that I’m feeling like I’ve done a lot of peopleing today and she’ll understand straight away what I mean, she’ll say ‘ok’ and she’ll leave me alone. She gets it and likewise, the same with her.” (Alice).</i> |
| | | <i>“I kind of instinctively kind of understood...what she was upset about or why she was upset...we’d have to then explain it to other people.” (Alice).</i> |
| | | <i>“There’s a clash of boundaries.” (Leah).</i> |

"instead of me being able to put my strategies in place to cope and deal with what I need and do what I need... I was doing stuff for her." (Sophie).

"Even when she is really annoying and being just not listening, normally it's due to a sensory thing, it's not cos she is being obnoxious... there's a clear like trigger for the behaviour." (Sophie).

Intrinsic Part of Self for
Better or Worse

"The appointments, school runs, I absolutely hate being on that school yard drop off and pick up, erm I don't go to any parent's events, I can't, I just can't deal with it." (Olivia).

"I'd prepared for the terrible two's long before they have even occurred, you know, thought about it before the baby's born." (Lucy).

"The sensory issues of the sound of carrying can be absolutely horrific." (Lucy).

"Both [Autism positive and negative for parenting] because its helped from the point of view of my ability to analyse, not see everything emotionally all the time is a good thing because it takes some of that out however my over emotion in certain things is more detrimental and it takes me a long time to get away from it because I hyper focus on things at times so yeah." (Emily).

"I think it's helped because to say its wholly got in the way would say that... I reject who I am and I don't." (Grace).

"It's just having to socialise with parents, because obviously I can't go to school and just say to a kid 'do you want to come to our house to play?' Just interact with the kid, play with the kid and then take them back. You always have to interact with the parents as well; there's always awkward conversations." (Zoe).

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| | | <p><i>"I just found it hard to know what to do, it wasn't, it's not like you know its scripted..." (Sophie).</i></p> <p><i>"I would say a bit of both [positives and negatives in relation to being autistic and parenting]. There are really amazing things about my brain, but at the same time there's some really quite disabling things about it." (Alice).</i></p> <p><i>"Professionals don't really like it when you know more than they do about the thing they're supported to be the professional at." (Alice).</i></p> |
| Battle for the Right Support | Others as Misunderstanding, Judging and Dismissive | <p><i>"I said 'he is Home Educated' and you could see her look concerned with that and then I said 'I'm Autistic' and then she looked concerned again." (Ava).</i></p> <p><i>"I can remember a point thinking 'no one's listening to me when I'm staying stuff but It's right, I can't keep looking at her and knowing that she is not getting support.'" (Sophie).</i></p> <p><i>"I referred her to CAMHS...they are like 'oh its parenting' because somewhere they had postnatal anxiety on my notes and they always assume it's just a parenting thing." (Sophie).</i></p> <p><i>"Everybody has an opinion then, especially when you've got an adopted child that they class as erm looked after and therefore in local authority care when they're not, erm so everybody treated him differently because of that." (Grace).</i></p> <p><i>"So all of the assumptions were wrong because they put their own spin on it, their own, their own feelings." (Grace).</i></p> <p><i>"...because neither of us have, um, apparently, high support needs? Like neither of us have a learning disability...demand overload doesn't seem to be something that registers as a need for any kind of official support." (Leah).</i></p> <p><i>"I just felt like I was constantly having to be on the defensive for my bodily integrity and have to be charming as well." (Leah).</i></p> |

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| | <i>"Why did you need a note from the doctor to believe what I'm actually telling you?" (Leah).</i> |
| Understanding ASC within the Family Unit | <p><i>"(NAME-husband) and I have started to praise each other now on how well we deal with three challenging children." (Olivia).</i></p> <p><i>"It's probably not a coincidence that I get on really well with Autistic people, so her kids both got a diagnosis as did both of mine, erm and we just became really good friends after we had kids." (Ava).</i></p> <p><i>"I think just having people to talk to, finding people in similar circumstances or similar experiences." (Sophie).</i></p> <p><i>"...one who gets it whose son hasn't got a diagnosis of anything but has lots of meltdowns and finds transitions hard...her mother in law was a SENCO I think and her...sister in law has adopted like a girl with autism so she just got it, and we are still in touch." (Sophie).</i></p> <p><i>"That's what I want to get support for after diagnosis rather than like general – 'oh here's a little bit of help' but like actually when there's two of you who are quite similar and you both get caught in the loop of the same things and the same things, similar things stress you out how do you deal with that?" (Sophie).</i></p> <p><i>"They're always very respectful and supportive, so - and it feels like an actual team, like it feels like we're each coming with our own expertise. So the teachers are coming with 'this is what we see in school' and we're coming from 'this is what we see at home' and then, you know, we're both there on like equal footing." (Alice).</i></p> <p><i>"Kind of recognising that it's all of us as a family that they're [school] trying to support." (Alice).</i></p> |

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| | | <p><i>"They actually understand a lot more about some of the issues...as [DAUGHTER]'s diagnosis has come along and my diagnosis has come along, I think we are in a much better place in a family now than we were." (Alice).</i></p> <p><i>"My sister...her son got an autism diagnosis...she completely got – like she really understands it. So having her support and understanding...has been like actually huge for the whole thing." (Leah).</i></p> |
| Development and Acceptance | Diagnosis, Self-Care, & Self-Acceptance. | <p><i>"I've been forced to look after myself better, I've learned more about Autism and my expectations of how much I can do." (Ava).</i></p> <p><i>"...from my perspective... now I know I'm Autistic I think it makes me a better parent, perhaps wasn't the case before I knew but I can adapt things now, I can understand myself better, I can have different sort of expectations of myself." (Ava).</i></p> <p><i>"I had known that was how it was and the black and white thinking was common with Autism, so now when I'm getting stressed about something part of me is like oh it's just because that's the way I'm processing stuff so I don't feel so bad all the time." (Sophie).</i></p> <p><i>"We have a Psychologist now and because we got the funding for me she is helping me to be me and then try and help (NAME-son) rather than trying to make me be something I wasn't." (Grace).</i></p> <p><i>"Since I found out its fantastic really, I re-write my whole life now with light bulb moments." (Grace).</i></p> <p><i>"...accepted that I just did other stuff with her, so we played a lot of music together, and read to her and puzzles or arts and craft." (Alice).</i></p> <p><i>"...I didn't have half of the knowledge and understanding about myself that I now have so it's been a big change." (Emily).</i></p> |

"I think there are moments where I'm now understanding I need some time away from things at times erm because as I'm becoming more aware of myself, my being Autistic" (Emily)

"I didn't know for then and so looking back its, its, I think I, because I didn't know wasn't as kind to myself as I should have been and I'd, I'd compared myself to people who were going to all these Baby Groups day in day out and I just looked at them with horror and thought I can't possibly do that." (Lucy).

"...Managing energy levels was... something that I now realise is key, I really didn't realise it in the early days...but that was probably because I had no clue what, what was draining me." (Lucy).

"...Once I got my diagnosis, I felt more... like I was allowed to say to the mother in law 'it would really help if you would have them once a week.'" (Zoe).

"...we've been able to.. understand, you know, just have a framework for what's going on, instead of, like I said, me seeking out this useless post-natal depression counselling that um, didn't really do much good at all." (Leah).

Growth and Adaptations

"We've just completely fitted our family life around mostly (NAME-son)'s needs and a little bit (NAME-daughter)'s but mostly (NAME-son) and were all happy now, life is a lot better since we've done that." (Ava).

"...We can't do stuff that other people do but I'm fine with that now, it, it took a bit of getting used to – due to child's need." (Ava).

"..Oh brilliant, like now I can learn from you as well as you learning from me." (Lucy).

"They've taught me how to communicate better as an Autistic person in Autistic ways and they've taught me how to communicate in non-autistic ways better accidentally." (Lucy).

"But I like to think those boundaries they sort of grow as the child grows and within those boundaries I like to leave them free to explore." (Lucy).

"Every stage they go through I say 'no, no stop at this one, this one is my favourite one, brilliant' and then they do something else and 'oh no, no this one, now this is my favourite one.'" (Lucy).

"Things like that with the parenting where you have to lie to your children, I don't like lying, I can't lie but obviously I'm not going to shatter your dreams as a child and (SIGH) we kind of had the whole tooth fairy thing and it's like 'well we will write a letter to the tooth fairy (NAME-son1)'...and we were really good writing this letter back...That was so creative for me, I was so proud of myself, it took me all night to write it (LAUGH)." (Olivia).

"Part from like I say that bit with feeding where I did get very upset about that but I think that's more about I wanted to do it a certain way and it wasn't going to happen that way erm yeah that's fine, I mean life happens and once I had finally accepted that and got past that." (Emily).

"He still wants to get into bed with us at times and he still wants to be with us, erm I think it's more about adapting and trying to ensure that we are also allowing him to be more independent at times but also making sure we meet his needs considering he's not following a neurotypical development." (Emily).

"I think we adapt as he changes and he adapts to us as life changes so yeah." (Emily).

"I've got a PDA profile even though it's not been diagnosed so she's fully aware of that so when we talk about parenting (NAME-son) she makes sure that she doesn't demand but suggests, lets me think then lets me help, helps me to choose and changes in a bite size manageable way and not in a very much a demanding way." (Grace).

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| The Ups and Downs of Parenting | Connection, Enjoyment and Rewards | <p><i>"Rewarding, its seeing her come on, erm yeah how she has developed and grown up, and, and seeing when we have made a good decision." (Ava).</i></p> <p><i>"Ups that it's really nice to have her around, do stuff with her, she is really hilarious so it's just nice having her around and she is very loving." (Ava).</i></p> <p><i>"It were cute listening to them babbling and teaching them words." (Zoe).</i></p> <p><i>"Just generally kind of like feeling love towards him, feeling proactive and feeling proud of him when he's achieved something or when he says something kind to [DAUGHTER] or finding him really funny. Just kind of wanting to be near him and wanting to hug him, kind of thing." (Alice).</i></p> <p><i>"He was always there and I was always there and we were always together." (Emily).</i></p> <p><i>"We used to play games or he used to sit there batting things around cheerfully there was definitely a connection there, erm yeah always there." (Emily).</i></p> <p><i>"I was that out of it on drugs and I didn't come round for about 3 hours...and then I held her... I didn't really feel anything.. it took like until...the next day [LAUGHS] for me." (Zoe).</i></p> <p><i>"I had a very difficult pregnancy and a very difficult birth, so I didn't really bond with her initially.. but I – I sort of pretended that I did" (Alice)</i></p> <p><i>"Suddenly the world had leverage on me than it had ever had before (LAUGHS); it was like there was something more important than anything else." (Leah).</i></p> <p><i>"Turbo cuddles and um, lots of really funny things he says (LAUGHS), he says crazy stuff all the time...it's just amazingly fun." (Leah).</i></p> |
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Managing Children's ASC /
Other Needs and Impact to
Self

"I think I did everything like a robot rather than it being like the breastfeeding I didn't enjoy it, it wasn't nice so it wasn't a bonding process it was a 'you need food, I have to feed you'." (Olivia).

"Practical getting by for those first few months than playing or laughing and smiling and because I spent a lot of it literally crying and sore". (Olivia).

"I am tired, physically tired and I can't ever see my life getting any less tiring." (Olivia).

"The breastfeeding because there were two of them, never left the sofa, it was horrible." (Olivia).

"Not many people could have handled that sort of level of stress, erm and it wasn't really relevant to mention Autism." (Ava).

"It [being autistic] probably made me more likely to get to that stage of being so stressed." (Ava).

"I used to feel guilty if I was doing things like something for me when they were babies and toddlers, if I was doing things for me I would feel really guilty." (Ava).

"I expected perhaps when they were small that that feeling of erm that of always being needed on a, and which I found actually quite difficult thinking about it, I found it really lovely when I didn't have to physically feed them anymore." (Lucy).

"You lose all your sleep, sleep is probably the biggest one." (Lucy).

"The harder thing is beating myself up over, you know have I got the right things in place for him, have I done the right thing." (Emily).

"Feeding him was tricky, he had a tongue tie nobody diagnosed...I was in tears every feed and we gave up eventually." (Emily).

“How much he ate, how much he didn’t eat, what he ate, what he didn’t eat, has he slept comfortably (LAUGH), does he like it, does he like being here, is he scared, was he happy, was it too remote where we live, did we have too many animals, did he feel pushed out because of the animals, did he like our routine, did he, you know everything.” (Grace).

“The whole process [adoption process] was awful and I was waiting for it to be over.” (Grace).

“That was the more kind of classic, you know... what if you know, what if we screw him up or whatever.” (Leah).

“It was incredibly difficult, the assessment process...the matching process [adoption processes]...very emotional kind of up and down.” (Alice).
